Predicting Negative, Positive and Ambivalent Outcomes in Informal Dementia Caregivers

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Abstract

Life expectancy is increasing in Australia and this trend is expected to continue with concomitant increase in the prevalence of dementia cases. As such, informal dementia caregivers are in high demand. The current literature has consistently highlighted the negative outcomes of the caregiving experience, however there is inconsistent research into potential positive outcomes and almost no research directed at relational ambivalence in caregivers. This study aimed to further our understanding of the variables in a caregiver's life that impact on their outcomes. Data from a cross-sectional survey of informal dementia caregivers (N = 91) was analysed using a hierarchical regression model based on Mackay and Pakenham's (2012) stress and coping model to assess three outcomes: negative, positive and ambivalent. The study revealed that the three outcomes were predicted by different variables, with relationship quality being the only variable that had an independent influence on all three. Distress was predicted by higher subjective burden, better relationship quality, and low optimism. Positive outcomes were predicted by caregiver sex (males experienced more positive outcomes), higher relationship quality and adopting problem-focussed coping styles. Ambivalence was predicted by higher subjective burden, poorer relationship quality, and not adopting problem-focussed coping styles. Future research should involve longitudinal studies and further application of this model to caregiver populations.

Keywords: Caregivers, Dementia, Ambivalence, Positive Outcomes

Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any University, and, to the best of my knowledge, this thesis contained no material previously published except where due reference is made. I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital thesis repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

Signed:

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I would like to acknowledge the hard work and dedication of my supervisor Dr. Lynn Ward who guided me and encouraged me, even when I thought I couldn't do it – thank you. And to my family I am eternally grateful. Although, you may live on the other side of the country I always felt supported and loved throughout this process and you helped me in every way possible. Thank you to my friends who were always around for me to de-stress and enjoy life with. I am appreciative of my fellow honours students who went through this journey with me. It's always nice to know there are others who are going through the same experience as you. I learned and grew from this experience and that is more than I can ask for.

Informal caregivers provide unpaid support to people who are unable to care for themselves due to an illness or disability, typically a relative or spouse (Australian Institute of Health and Welfare [AIHW], 2012). This study is concerned with informal caregivers, rather than those who care in a professional capacity, and will herein refer to them simply as caregivers. Approximately 12% of Australians (Australian Bureau of Statistics [ABS], 2012b) are in caregiving roles with an estimated economic value of informal care in Australia of $60.3 billion in 2015 (Carers Australia, 2015). Of the 2.7 million caregivers in Australia, approximately 200,000 of these are providing care for someone with dementia (AIHW, 2012). Dementia is a neurocognitive disorder that typically occurs later in life however is not synonymous with normal ageing (World Health Organisation [WHO], 2012). Dementia presented in approximately 35.6 million people worldwide in 2010 and this figure is projected to double every 20 years (WHO, 2012). This growth can be attributed to the ageing of the population (Waite, Connelly, Harwood & Morton, 2008); the percentage of people over 65 years in Australia has grown from 12.6% in 2003 to 14% in 2012 and is predicted to increase steadily (ABS, 2012b). As such, the Department of Health (2018) have declared dementia a National Health Priority Area. In addition to the growing need for dementia caregivers, Australia has seen a fall in the propensity to care, resulting in a gap between demand and supply that is predicted to increase (Carers Australia, 2015).

In light of the increasing prevalence of dementia and the need for informal caregivers, there is a need to address outcomes for caregivers. Previous research around caregiver (CG) outcomes has revealed that this role can cause strain on mental health, financial status, physical health and the education and employment opportunities of the CG (WHO, 2012; AIHW, 2017).

However, a more recent and underdeveloped body of research has considered the positive outcomes of caregiving (Kramer, 1997; Lloyd, Patterson & Muer, 2016). This research is lacking consistency and conceptualisation, requiring further examination of predictors and appropriate assessment techniques (Carbonneau, Caron & Desrosiers, 2010; Kramer, 1997). In addition to positive and negative outcomes an emerging field of research has focused on relational ambivalence in caregivers (Losada, Pillemer, Márquez-González, Romero-Moreno, & Gallego-Alberto, 2016). This construct reflects co-occurrence of high positive and high negative affect toward a person. There is an identified gap in the literature whereby the predictors of relational ambivalence in caregivers are unknown and those of positive outcomes are generally under-researched.

The aim of this study was to assess the predictors of negative, positive and ambivalent outcomes of caregivers for individuals with dementia using a transactional model of stress and coping (Mackay and Pakenham, 2012). The Mackay and Packenham model considers predictor variables under broad headings of *background variables*, *coping resources*, *appraisal*, and *coping strategies*. It has been successfully been applied in previous studies of caregiving groups including caregivers of individuals with Borderline Personality Disorder (Oakey-Neate, n.d.) and Multiple Sclerosis (Pakenham, 2001).

1.1 Defining Dementia

Dementia is a neurocognitive disorder resulting from physical changes to the brain structure (Zarit & Talley, 2013). There are many forms of dementia, with the most common form being Alzheimer's disease, accounting for 50 - 75% of dementia cases (Karantzoulis & Galvin,

2011). Other common forms of dementia include vascular dementia and frontotemporal dementia, each with varying clinical manifestations and etiologies (Zarit & Talley, 2013). Dementia is defined by a global set of symptoms relating to impairment of cognitive processes, particularly memory, and changes to personality and behaviour (Waite et al., 2008). Other symptoms include confusion about time and place, inability to comprehend and express language and inability to control movement (Waite et al., 2008). The onset of these symptoms is typically gradual and the primary marker of dementia is decline in memory functioning (WHO, 2016). Behaviour changes occur in 65% of people with dementia during the course of the disorder (Waite et al., 2008); these can include mood changes, delusions and apathy (Karantzoulis & Galvin, 2011). Behaviour changes have been associated with a more rapid decline in ability, increase in cost of care and higher consumption of medication (Karantzoulis & Galvin, 2011). The symptoms and severity of dementia vary between individuals; nonetheless the condition is irreversible and worsens over time (Zarit & Talley, 2013).

1.2 Caregiving Experience and Outcomes

Providing care for someone with dementia has been described as more demanding and stressful than other care situations (Zarit & Talley, 2013) as it typically requires longer hours of care and is terminal (AIHW, 2012). Caregiving roles may include activities such as medical care, self-care, communication and transportation assistance, where the care-recipient (CR) cannot perform these tasks independently (Australian Bureau of Statistics [ABS], 2012b). Behavioural changes, particularly depression in the CR, and change to the relationship have been cited as the most distressing to dementia caregivers (Teri, 1996; Carbonneau et al., 2010; Pinquart & Sorensen, 2003a). Outcomes for caregivers are reviewed in the following sections.

1.2.1 Negative Outcomes for Caregivers. There is extensive research on how providing care for a loved one with dementia can have a detrimental effect on wellbeing (Lloyd et al., 2016; Pinquart & Sörensen, 2003b; Tarlow, Wisniewski, Belle, Rubert, Ory & Gallagher-Thompson, 2004). With regards to mental health outcomes for caregivers in general, evidence suggests that compared to non-caregivers, they exhibit increased levels of stress (González-Salvador, Arango, Lyketsos & Barba, 1999), higher risk of depression and anxiety (Hirst, 2004; Mausbach, Chattillion, Roepke, Patterson & Grant, 2012; Pinquart & Sörensen, 2003b), higher reporting of suicidal thoughts (Stansfeld et al., 2014), and increased guilt (Losada, Márquez-González, Vara-García, Gallego-Alberto, Romero-Moreno & Pillemer, 2017). Further to the mental health impacts, caregivers have been shown to experience downturns in physical health while caregiving (Kasuya, Polgar-Bailey & Takeuchi, 2000) with increased blood pressure (King, Oka & Young, 1994) and lowered immune responses compared with non-caregivers (Vedhara et al., 1999). These health concerns are exacerbated in dementia caregivers as they may be compounded by the CGs own age-related pathological decline (O'Connell, Bailey & Walker, 2003). Financial struggle and limitations to the caregiver's social and personal lives are also common outcomes of caregiving (Kasuya et al., 2000). A report by MetLife Mature Market Institute (2011) estimated that individual income loss due to leaving the workforce early for caregiving roles is upwards of $300,000 USD in the United States. Similarly, the ABS (2012b) states that caregivers are more likely than non-caregivers to be in the lowest household income categories. Disagreements about finances and responsibility can also lead to conflict in families (WHO, 2012).

1.2.2 Positive Outcomes for Caregivers. In theory, positive outcomes are not simply the absence of negative outcomes but rather represent a separate category in a bivariate model (Cacioppo, Gardner & Berntson, 1997). Compared to the extensive research into negative outcomes of caregiving, less research has been dedicated to the potential positive outcomes of the role (Lloyd et al., 2016; Ma, n.d.; Rapp & Chao, 2000). George and Gwyther (1986) suggested that a multi-dimensional study of caregiver outcomes would be beneficial in understanding the full scope of the role. Since then, research into the positive aspects of caregiving has increased; however critical reviews of the literature highlight the lack of definition for the outcome (Carbonneau et al., 2010; Kramer, 1997; Lloyd et al., 2016). Various conceptualisations of positive outcomes of caregiving have been utilised in early studies including satisfaction from the role (Cohen, Colantinio & Vernich, 2002; Kramer, 1993; Talkington-Boyer & Snyder, 1994), derivation of meaning (Farran, Keane-Hagerty, Salloway, Kupferer & Wilken, 1991), personal gains (Pearlin, Mullan, Semple & Skaff, 1990) and uplifts (Kinney & Stephens, 1989). A number of different theoretical frameworks such as the stress process (also known as stress and coping) models (Kinney & Stephens, 1989; Pakenham, 2001; Pearlin et al., 1990; Picot, 1995), existentialism (Farran et al., 1991) and social exchange theory (Walker, Martin & Jones, 1992), in which positive aspects are sometimes considered appraisals and other times, outcomes have also been utilised. Hence, inconsistencies have been found as to how positive aspects operate in the context of caregiving and what predicts them (Kramer, 1997).

Previous quantitative and qualitative research has shown that many caregivers cope well and have a rewarding experience (Cohen et al., 2002; Sanders, 2005). A critical review of the qualitative literature by Lloyd et al. (2016) found that the main positive domains reported by

caregivers are role satisfaction, emotional rewards, personal growth, competence and mastery, faith and spiritual growth, relationship gains, sense of duty and reciprocity. Caregivers perceive the positive aspects as the result of their own choices, strategies and mechanisms (such as commitment, acceptance and attitude) (Farran et al., 1991; Lloyd et al., 2016). Research into positive outcomes of caregiving, particularly using quantitative methodologies, can contribute to unique, directed support for harnessing positive outcomes and improving caregiver's mental health and overall life satisfaction (Carbonneau et al., 2010; Kramer, 1997; Rapp & Chao, 2000).

1.2.3 Ambivalent Outcomes for Caregivers. Attitudes and affect are typically categorised into a bipolar dimension, wherein positive is the direct opposite of negative on a continuum (Cacioppo et al., 1997). This view neglects the reality that simultaneous endorsement of both attitudes towards a singular object or person can occur. When simultaneously high negative and high positive affect towards one object occurs this is referred to as ambivalence (Cacioppo et al., 1997; Gilligan, Suitor, Feld & Pillemer, 2015; Lavine, 2001), not to be confused with low negative and low positive endorsement, which is referred to as neutrality or indifference (Cacioppo et al., 1997). Ambivalence is present in many aspects of daily life, including relationships (relational ambivalence), whereby a person feels ambivalent about another person. Relational ambivalence is prominent in intergenerational relationships (Gilligan et al., 2015; Fingerman, Pitzer, Lefkowitz, Birditt & Mroczek, 2008), workplace relationships (Rothman, Pratt, Rees & Vogus, 2017; Ingram, 2012), spousal relationships (Uchino, Smith & Berg, 2014) and recently it has been identified in caregiving relationships (Losada et al., 2016; Shim, Barroso & Davis, 2012).

In previous studies ambivalence has been related to negative outcomes (Gilligan et al., 2015; Rothman, et al., 2017) such as depressive symptomatology (Losada et al., 2017), psychological distress (Fingerman et al., 2008) and difficulty in making decisions and taking action (Braverman, 1987). A study by Losada et al. (2017) subsequently showed the mediating effect of guilt on the relationship between ambivalence and negative outcomes.

It is unclear exactly what causes ambivalence. In their qualitative study, Shim et al. (2012) found that ambivalence could develop through feelings of frustration toward a changing relationship. Losada et al. (2016) suggested that conflicting norms, expectations and roles could be cause for caregiving ambivalence. An alternate explanation is that internal processes and individual differences contribute. This could reflect differences in cognitive styles such as representations of the self and emotions (Hui, Fok & Bond, 2009; Rafaeli, Rogers & Revelle, 2007) making some people more susceptible to experiences of ambivalence and more distressed by the experience (Braverman, 1987; Fingerman, Chen, Hay, Cichy & Lefkowitz, 2006; Rothman et al., 2017).

Ambivalence can be measured indirectly using a score calculated from ratings on independent measures of positive and negative affect, (Thompson, Zanna, and Griffin, 1995 as cited in Gilligan et al., 2015). According to this method, a high ambivalence score occurs when both positive and negative sentiments are high (Gilligan et al., 2015). This method has been criticized for incorrectly associating negative outcomes with ambivalence when in fact they are mostly due to high scores on the negative component of the measures, with the positive component having little impact (Gilligan et al., 2015). As an alternative, ambivalence can be

measured by items that directly address the co-existing occurrence of opposing feelings, as in the Caregiver Ambivalence Scale (CAS) developed by Losada et al. (2016). An example item from the CAS reads: '*I feel as much satisfaction as resentment (rage) by being a caregiver'*.

1.3 Stress and Coping Model

Lazurus and Folkman's (1984) transactional theory of stress and coping is a widely used framework to explain the process through which a person experiences and interprets stressful situations or events, such as caregiving (e.g. Kramer, 1993; Pakenham, 2001). The theory suggests that a person's appraisal of a situation and how it corresponds with their available *coping resources* and *strategies* determines their adjustment outcomes. The process is dynamic and considers stress as a transaction rather than an outcome or stimulus (Lazarus & Folkman, 1984). The stress and coping model by Mackay and Pakenham (2012) is a hierarchical regression model based on this theory, which was originally developed and tested on a group of informal caregivers of people with mental illness. *Background variables*, *coping resources*, *appraisal* and *coping strategies* are the predictor variables in the stress and coping model with benefit finding, *positive affect*, *life satisfaction*, *physical health* and *psychological distress* as the adjustment outcomes (shown graphically in Figure 1). The model predicted 64% of distress outcomes and between 26-48% of positive outcomes in Mackay and Packenham's (2012) study.

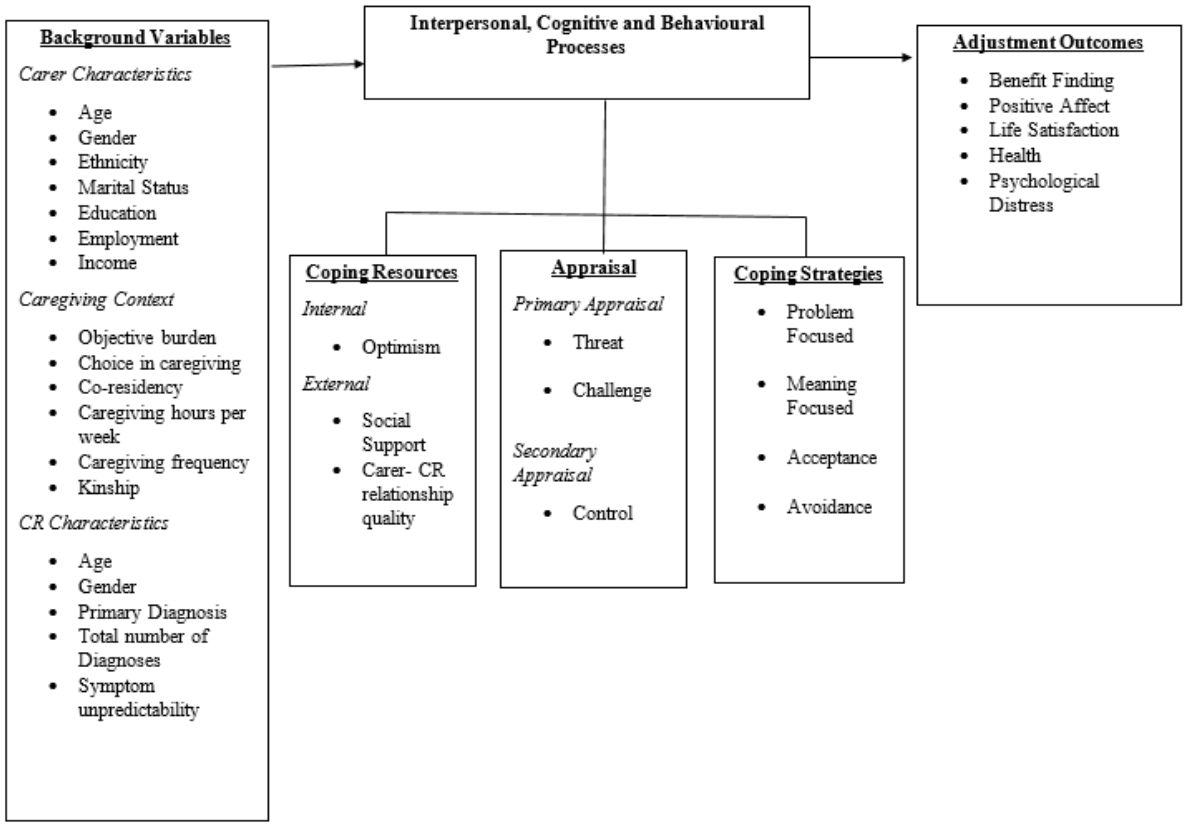

Figure 1 Mackay and Pakenham's (2012) Model of Caregiving

1.3.1 Background Variables. The *background variables* in the model include caregiver characteristics, CR characteristics and the caregiving context. Because the current study was concerned with distress, positive aspects and ambivalence as outcomes the physical health outcome from Mackay and Pakenham's (2012) model was moved to *background variables* so that the effects of it could be controlled for. Other dementia caregiver studies have also considered physical health as a *background variable* (e.g. Brodaty & Hadzi-Pavlovic, 1990). Mackay and Pakenham's (2012) study found that *background variables* accounted for 7-22% of the outcome variables. Higher hours of care per day and CR symptom unpredictability predicted higher distress. Higher objective burden was related to higher distress and lower life satisfaction (Mackay and Pakenham, 2012). In the wider caregiving literature, studies have found that

providing care in your residence and higher hours of care per day can contribute to psychological distress (Gonzalez-Salvador et al., 1999; Hirst, 2004; Losada et al., 2017). Caregiver depression increases as burden increases and self-rated health decreases (Schulz, O'Brien, Bookwala & Fleissner, 1995; Williamson & Schulz, 1992). *Background variables* have also been shown to relate to positive outcomes. For example lower education and being married have been related to positive outcomes (Grover, Nehra, Malhotra & Kate's, 2017) however the effects were small. The effects of age on positive outcomes are mixed; some found that older caregivers reported more positive outcomes (Talkington-Boyer & Snider, 1994), whereas others reported the opposite (Kramer, 1993). Higher burden leads to lower positive outcomes (Tarlow et al., 2004). Losada et al. (2017) found that ambivalence is higher in younger caregivers and parent-child dyads. Other situational aspects such as lowered CG physical health and more time spent together can increase ambivalence (Fingerman, 2006; Losada et al., 2016; Brooks & Highhouse, 2006). Finally, being female was linked to higher responses on negative (Pinquart & Sörensen, 2006) and ambivalent (Losada et al., 2016) outcomes; however, in general, sex differences in caregiving are inconsistent and inconclusive (Sharma, Chakrabarti & Grover, 2016).

1.3.2 Coping Resources. *Coping resources* are viewed as relatively stable characteristics of the environment or individual, which facilitate positive adjustment in stressful situations (Billings & Moos, 1982). The three *coping resources* used in the Mackay and Packenham model are: social support, caregiver-care recipient relationship (relationship quality) and optimism. Higher optimism, relationship quality and social support are related to lower distress and higher positive affect (Mackay & Packenham, 2012). In broader research, social support and relationship quality have been found to protect against negative outcomes (Pearlin et al., 1990;

Stansfeld et al, 2014; Walker et al., 1992). Optimism has been related to lower depression in a study of cancer caregivers; however, optimism research in the stress and coping context is scarce (Given et al., 1993). Higher positive outcomes have correlated with higher social support and relationship quality (Kramer, 1993; Talkington-Boyer & Snyder, 1994; Tarlow et al., 2004). Relationships between *coping resources* and ambivalence have not been examined in the literature.

1.3.3 Appraisal. *Appraisal* is the cognitive process of responding to environmental stimuli and interpreting subjective experience (Lazarus & Folkman, 1984). The stress and coping theory, outlined by Lazarus and Folkman (1984), defines *appraisal* in two stages, primary and secondary. Primary appraisal is the process of evaluating something as a threat, benign or a challenge and secondary appraisal refers to the extent to which a person views an event or situation as within their control. In the Mackay and Pakenham (2012) study, higher threat appraisals were linked to distress and lower life satisfaction, and higher challenge appraisals were linked to higher benefit finding and positive affect. Controllability (secondary appraisal) had no effect. In the wider literature, higher threat appraisals have been related to higher levels of distress and negative mood (Pakenham, 2001; Stanton & Snider, 1993). Relationships between secondary appraisal and outcomes have been weak or non-existent (Pakenham, 2001; Fitzell & Pakenham, 2010; Stanton & Snider, 1993).

There are alternative and equally effective ways of framing appraisal in the literature, such as perceived stress (Schulz et al., 1995) or caregiver's subjective experience of burden (Kinney & Stephens, 1989; López, López-Arrieta & Crespo, 2005). After considering the appraisal research

and the lack of impact of the secondary appraisal in previous studies (Mackay & Pakenham, 2012; Stanton & Snider, 1993) the current study conceptualised *appraisal* as subjective burden. This study utilised the subjective burden subscale of the Burden Assessment Scale (Reinhard, Gubman, Horwitz & Minsky, 1994) to measure *appraisal*. Further justification for inclusion of the subjective burden subscale as an appraisal measure was to eliminate redundant questions – the objective burden subscale and the original appraisal scale used by Mackay and Packenham had considerable overlap in question content.

1.3.4 Coping Strategies. Lazarus and Folkman (1984) define *coping strategies* as flexible cognitive and behavioural methods of managing demands that are perceived as stressful and exceeding a person's resources. They identify that *coping strategies* are difficult to measure and have many conceptualisations. Two general coping factors are cited in Folkman & Lazarus (1980) that have endured in the literature, these are emotion-focussed and problem-focussed coping. Problem-focussed coping involves actions aimed at altering the stressor, whereas emotion-focussed coping involves managing the resulting emotions of the stressor (Carver, Scheier & Weintraub, 1989). However, there is concern over the efficacy of this categorisation and there are other ways to categorise *coping strategies* (Carver, 1997; Carver, et al., 1989). The Mackay and Pakenham (2012) stress and coping model utilised the Brief-COPE scale (Carver, 1997), measuring a wide range of coping styles, on 14 subscales. Exploratory factor analysis was used to identify factors from the data. Mackay and Pakenham (2012) fit four secondary factors to their data: problem-focussed, emotion-focussed, avoidance and acceptance. *Coping strategies* did not play a large part in predicting outcomes in Mackay and Pakenham's (2012) study of caregivers for people with mental health problems, with the only significant relationship being

that less reliance on avoidance coping predicted lower distress. Avoidant coping styles are related to distress in mental health caregivers (Goossens, Van Wijngaarden, Knoppert-Van Der Klein & Van Achterberg, 2008). Other than the effect of avoidance coping on negative adjustment outcomes, there is inconsistency in the caregiving literature about other forms of coping and their outcomes (Mackay & Pakenham, 2012).

1.4 Current Study

The purpose of the current study is to examine predictors of negative, positive and ambivalent outcomes in caregivers of loved ones with dementia. The study addresses identified gaps in the literature, which are (1) the lack of consistency and appropriate research design in assessing predictors of positive outcomes in caregivers and (2) the lack of research directed at predictors of ambivalence in caregivers. Negative outcomes were also assessed for comparisons with the positive and ambivalent outcomes. The Mackay and Packenham stress and coping model was utilised to examine the effect of *background variables, coping resources, appraisal* and *coping strategies* on the aforementioned outcomes. Combining the comprehensive stress and coping model with effective outcome measures should allow for a good understanding of positive and ambivalent outcomes, which has been a weakness of the previous literature. Details of the proposed regression relationships between variables in the model and the outcomes are shown in Table 1 below. These predictions are based on the Mackay and Pakenham (2012) study on mental health caregivers as well as the review of the literature into dementia caregivers more specifically.

Table 1 Predicted Contributions to Outcome Variables

Predictor Variable	Distress	Positive Outcomes	Ambivalence
Physical health	+		+
Objective burden	+	-	
CG sex (male)	-		-
CG age			-
Education		-	
Relationship type (parent-child)			+
Co-residency	+		
Hours of care per day	+		+
Marital status (married)		+	
Optimism	-	+	
CG-CR relationship quality	-	+	
Social support	-	+	
Subjective burden	+	-	

2 Method

2.1 Participants

Participants were informal caregivers of a loved one with dementia (N = 112). Of these, 21 participants were removed due to either: incomplete datasets (N = 14), having more than one care recipient (CR) (N = 2) or no longer providing care (N = 5), leaving 91 participants for the analysis. Eligibility criteria included only those people who were over 18 years old, proficient in English comprehension and currently the primary caregiver for a spouse or family member with dementia. They must have been providing care for at least 3 months and at least 1 hour per day. The descriptive statistics for the *background variables* are displayed in Table 2. Spousal caregivers made up 48.4% of the sample, 44% were caring for a parent and 7.7% selected 'other'; open-ended responses revealed they were caring for a child, grandparent, ex-spouse or parent-in-law. Co-residency was the norm in this sample (71.4%). Caregiver age ranged from 28 to 83 (M = 64, SD = 9.8) and the CR age ranged from 58 to 98 (M = 81, SD = 10.5). The majority of respondents were female (79.1%) and their CR counterparts were 47.3% female. This overrepresentation of female CGs is also the case with Australian caregivers in general (ABS, 2012b). Of the respondents, 33% were employed, compared to 62% of the Australian population according to the ABS (2012a); this was expected given the age group and the demands of caregiving. The study participants were more highly educated than the general Australian population with 39.6% completing a bachelor or higher qualification compared to 24% of the general population (ABS, 2012a). Of the study participants, 26.4% had not completed qualifications beyond school (Cert I and II excepted) compared with 47% of the general population (ABS, 2012a). Majority of the respondents were from NSW (82.4%) due to circulation of the survey details in a popular NSW senior's magazine. Most participants

identified as Australian (79.1%), other cultures represented were Asian (5.5%), British (5.5%), European (4.4%), New Zealander (3.3%) and Indian (1.1%). As expected, the most common type of dementia was Alzheimer's disease (31.9%), with other represented types including vascular dementia (14.3%) and frontotemporal dementia (13.2%) (see Table 2 for details).

Table 2 Descriptive Statistics - Sociodemographic Variables

Variable		*Mean* (*SD*)	Range	*N*	%
Situation Variables					
Hours of care per day		12.1(9.5)	1-24		
Length of care					
	Less than 6 months			3	3.3
	6 months to 1 year			8	8.8
	1-5 years			56	61.5
	6-10 years			20	22.0
	Longer than 10 years			4	4.4
Relationship type					
	Spouse			44	48.4
	Son/daughter			40	44.0
	Other			7	7.7
Co-residency					
	Yes			65	71.4
	No			26	28.6
Caregiver Variables					
Age		64.1(9.8)	28-83		
Sex					
	Male			19	20.9
	Female			72	79.1
Employment					
	Full time			7	7.7
	Part time			15	16.5
	Casual			8	8.8
	None			61	67.0
Education					
	Yr 9 or below			3	3.3
	Secondary school/Cert I or II			21	23.1
	Cert III or IV			11	12.1
	Diploma/advanced diploma			18	19.8
	Bachelor or above			36	39.6
	Choose not to answer			2	2.2
Physical health					
	Excellent			14	15.4
	Very good			26	28.6
	Good			36	39.6
	Fair			13	14.3
	Poor			2	2.2
State					
	NSW			75	82.4
	QLD			5	5.5
	SA			3	3.3
	NT			3	3.3
	VIC			2	2.2
	WA			2	2.2
	TAS			1	1.1
Ethnicity					
	Australian			72	79.1

	Asian			5	5.5
	British/Irish			5	5.5
	European			4	4.4
	New Zealander			3	3.3
	Indian			1	1.1
	Choose not to answer			1	1.1
Marital status					
	Married/de facto			71	78.0
	Separated/divorced			6	6.6
	Widowed			2	2.2
	Never married			10	11.0
	Choose not answer			2	2.2
Care Recipient Variables					
Age		80.9(10.5)	58-98		
Sex					
	Male			43	47.3
	Female			48	52.7
Dementia type					
	Alzheimer's			29	31.9
	Vascular dementia			13	14.3
	Frontotemporal dementia			12	13.2
	Mixed dementia			7	7.7
	Dementia with Lewy bodies			6	6.6
	Creutzfeldt-Jakob diseaase			3	3.3
	Parkinson's disease			3	3.3
	Huntington's disease			1	1.1
	Not sure			11	12.1
	Other			9	9.9
Comorbidity					
	Yes			38	41.8
	No			53	58.2

2.2 Measures

The online survey included socio-demographic questions about the caregiving situation (4 items), the caregiver (8 items) and care recipient (4 items), and 8 self-report scales based on the stress and coping model (Mackay and Pakenham, 2012), with some modification in line with the research aims, as specified below.

2.2.1 Socio-demographic measures. Questions related to the caregiving situation included hours of care provided per day, length of time spent in the caregiving role, co-residency and relationship to care recipient. Questions relating to demographic information of the caregiver included the caregiver's age, sex, employment, education, perceived physical health status (rated from 1 = *excellent* to 5 = *poor*), state of residence, ethnicity and marital status. Questions relating to the care-recipient included their age, sex, type of dementia diagnosis (e.g. Alzheimer's disease, vascular dementia, frontotemporal dementia), and whether or not they had any other diagnoses. Variables were selected based on previous research and what might be expected to impact on outcomes.

2.2.2 Burden Assessment Scale (BAS; Reinhard et al., 1994). The BAS required participants to rate their level of burden in relation to caregiving on 19 items comprising two subscales to measure both objective and subjective burden. Ten items measured the experience of observable, objective burden such as financial issues and disruptions to personal and household activities e.g. *'had financial problems'.* The remaining nine items measured subjective aspects of burden such as guilt, worry and resentment e.g. *'Found the stigma of the illness upsetting'.* Responses reflected the extent to which the participant had experienced each item in the past six months as a direct result of their loved-one's illness. The responses were rated on a four point Likert-type scale from 1 = *Not at all* to 4 = *a lot.* There was also an option for 9 = *Not applicable* which was taken as missing data in analyses and the remaining scores were averaged across the number of questions answered to give a score for the scale. Possible scores for both scales ranged from 1 to 4. Higher scores indicated higher levels of burden. In previous use the scale has displayed good reliability, Cronbach's α of .90, and good validity (Reinhard et al.,

1994).

2.2.3 Life Orientation Test-Revised (LOT-R: Scheier, Carver & Bridges, 1994). The LOT-R scale was used to measure optimism. This scale contained ten items (e.g '*In uncertain times, I usually expect the best'*), rated on a five point Likert-type scale from 0 = *strongly disagree* to 4 = *strongly agree*. Six items were used to determine optimism scores, and four were filler items. Half of the items were reverse coded before scoring due to negative wording. Item scores were then summed to determine an overall optimism score; higher scores indicated a more optimistic personality with possible scores ranging from 0 to 24. The LOT-R has previously reported satisfactory internal reliability, Cronbach's α = .78, and validity (Scheier et al., 1994).

2.2.4 Social Support Questionnaire - 6-item (SSQ6; Sarason, Sarason & Shearin, 1987). The SSQ6 is a revised version of the 27-item Social Support Questionnaire (Sarason, Levine, Basham & Sarason, 1983, Cronbach's α = .97). The scale measures both perceived availability (quantity) of and satisfaction (quality) with social support. Perceived availability was measured by the number of people the participant could list who provide support in six domains (maximum five people per question), for example *'Whom can you really count on to distract you from your worries when you feel under stress?'.* Quality was measured on a six point Likert-type scale ranging from 1 = *Very Dissatisfied* to 6 = *Very Satisfied.* The satisfaction aspect of the question from the previous example was *'In relation to the above question, how satisfied are you?'.* Scores were summed per subscale to provide an overall score for both perceived availability and satisfaction, separately; higher scores indicated more social support and higher satisfaction, respectively. Possible scores for perceived availability ranged from 0 to 30 and for satisfaction

ranged from 6 to 36. Cronbach's α for the SSQ6 is between .90 and 93 for both perceived availability and satisfaction subscales (Sarason et al., 1987).

2.2.5 Quality of the Caregiver-Care Recipient Relationship (CCRR; Mangen, Bengston & Landry, 1988). This scale used four questions to measure different aspects of the relationship between the caregiver and the CR, i.e. closeness, communication, getting along and similarity in views. For example *'generally, how well do you and your CR get along together?'.* Responses were measured on a four point Likert-type scale ranging from 1 = *not at all close/well/similar* to 4 = *very close/well/similar* with higher scores indicating a better quality relationship. The possible scores ranged from 4 to 16. Cronbach's α for the CCRR is .85 (Lawrence, Tennstedt & Assmann, 1998).

2.2.6 Brief-COPE 28-Item (Carver, 1997). The Brief-COPE consists of 28 items that assess dispositional coping styles in response to high stress situations. It is a condensed version of the original COPE scale (Carver et al., 1989) which has a Cronbach's $\alpha > .60$ for all subscales but one, which was removed from the Brief-COPE. The Brief-COPE has 14 subscales with two items per subscale to measure the different styles of coping. The 14 subscales of the Brief-COPE are self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame. Participants rated the extent to which they usually use each coping style when they experience a stressful event. The responses were measured on a five point Likert-type scale that ranged from 1 = *I usually don't do this at all* to 4 = *I usually do this a lot*. Each subscale had a possible score range of 2 to 8. Cronbach's α for the Brief-

COPE ranges from .62 to .92 (Carver, 1997). The subscales were subjected to principle components analysis in the data analysis to reveal second order factors for ease of interpretation.

2.2.7 Depression Anxiety Stress Scales – 21-item (DASS-21; Lovibond & Lovibond, 1995). The DASS-21 is a 21 item self-report questionnaire measuring three dimensions of distress: depression, anxiety and stress. It is a condensed version of the 42-item DASS (Lovibond & Lovibond, 1995), which has shown excellent validity with a Cronbach's α ranging from .92 to .97 for the different scales (Antony, Bieling, Cox, Enns & Swinson, 1998) and excellent reliability (Crawford & Henry, 2003). Each subscale consisted of seven questions and responses were measured on a four point Likert-type scale from 0 = *did not apply to me at all* to 3 = *applied to me very much, or most of the time*. Scores were doubled for comparison with DASS-42 cut off-scores; therefore each subscale can range from 0 to 42 with higher scores indicating higher levels of that construct. Scores can be computed for respective subscales or as a whole distress score. Cronbach's *α* for the DASS-21 subscales range from .87 to .94 (Antony et al., 1998).

2.2.8 Positive Aspects of Caregiving Scale (PAC; Tarlow et al., 2004). The PAC measures different positive outcomes that have previously been associated with caregiving. It comprised of nine questions such as *'providing help to my loved one with dementia has made me feel more useful'*. Participants rated the extent to which they agreed with each statement on a five point Likert-type scale ranging from 1 = *disagree a lot* to 5 = *agree a lot* with higher scores relating to more positive outcomes. Possible scores ranged from 9 to 45. The Positive Aspects of

Caregiving scale has a Cronbach's α of .89 and has demonstrated moderate convergent and discriminant validity (Tarlow et al., 2004).

2.2.9 Caregiver Ambivalence Scale (CAS; Losada et al., 2016). This scale was designed to measure the extent to which a dementia caregiver feels both high positive and negative feelings toward the caregiving situation simultaneously. The scale addresses ambivalence directly using questions such as *'I feel divided or in conflict with respect to issues related to my relative'.* The CAS comprises of six items measured on a four point Likert-type scale from 0 = *never* to 3 = *always*. Possible scores ranged from 0 to 18 with higher scores equating to higher levels of ambivalence. The CAS has a Cronbach's α of .86 (Losada et al., 2016).

2.3 Procedure

Passive snowball sampling was used to recruit participants. Organisations having potential affiliations with informal dementia caregivers were sent a letter (Appendix 1) asking them to circulate the invitation to their members. Appropriate organisations were identified using an Internet search, which used keywords such as 'dementia', 'support', 'Australia', 'aged care', 'seniors' etc. The results of the search are shown in Appendix 2. Circulation of the invitation letter (Appendix 3) and/or flyer (Appendix 4) occurred via means such as newsletters, websites and social media. Additionally, the flyer and invitation letter were circulated through personal networks of the researchers and through community notice boards. Participants could then access the survey via the included link. Participants were also offered the chance to complete the study via paper and pencil copy, which was mailed to them if they requested this. The project was

approved by the Human Research Ethics Committee of Adelaide University, approval number H-2018-098.

Participants who followed the link on the invitation letter or flyer were directed to the online survey, hosted by SurveyMonkey™. The study consisted of a 126 question self-report questionnaire (Appendix 5). The first page of the survey was the information sheet, which included a consent statement and counselling support contacts if necessary. Following this, sociodemographic questions, eight measurement scales, and one qualitative question were presented. The qualitative question read *'Thinking about the outcomes of caregiving, would you like to add anything about your experience? We would love to hear your thoughts, whether you think it will contribute to the study or not'.* Response to this question was optional and a total of 60 respondents chose to answer it. Analysis of the results from this question was beyond the scope of the current study.

3 Results

3.1 Data Screening

The data were analysed using the statistical package, SPSS, Version 25. Raw data were screened for outliers and normality using the Shapiro-Wilk and Komolgorov-Smirnov tests together with visual inspection of box-plots and Q-Q plots, revealing that only the Caregiver Ambivalence Scale (CAS), the Positive Aspects of Caregiving scale (PAC) and the objective burden subscale of the Burden Assessment Scale (BAS) met the criteria for normality. The 5% trimmed means for the non-normally distributed scales were assessed and did not differ significantly from their relative means, with the exception of the DASS-21 scale. Hence, the DASS-21 scale was transformed using a square root function for the analysis; the non-transformed descriptive statistics are reported. The DASS-21 measure revealed one particular outlier with a z-score of 3.79; however, the open-ended response for this case explained the extreme distress for the participant stating: *'Having gone through this with my mum for 3 years before she died and now my dad for past 4 years I'm physically and mentally exhausted but I just push myself to keep going because he was a great dad and he has no one else."* Therefore, the data were considered legitimate and remained in the analyses. In responses to the question about relationship type, 7% of cases originally selected that they were the parent of the care recipient (CR) – it is suspected that these people meant to select son/daughter but did not read the question properly. This was confirmed by comparing the respective ages of caregiver (CG) and CR, with the exception of one case, which was in fact a parent caring for a child with dementia. This is reflected in the reported statistics.

3.2 Exploratory Factor Analysis for Brief-COPE Scale

Exploratory factor analysis based on the data set is recommended for the Brief-COPE scale (Carver, 1997) to identify higher-order factors (Carver, n.d.). Principal components analysis (PCA) was deemed the most appropriate method of extracting appropriate underlying components for the 14 subscales of the Brief-COPE (Carver, 1997) measure. Oblique rotation (Oblimin) was employed as correlation of the underlying components was expected (Field, 2009). PCA with oblique rotation was also used in the analysis conducted by the authors of the original COPE measure (Carver et al., 1989). Trial and error of other methods was conducted and the reported analysis yielded the best results.

There were no correlations between subscales greater than .60, ensuring they were adequate for PCA (Field, 2009). The initial analysis revealed that individual Measures of Sampling Adequacy (MSA) values for the following subscales were unacceptable, < .5 (Field, 2009): self-distraction, denial, substance abuse, emotional support and self-blame. Ongoing analyses omitted these variables. The Kaiser-Meyer-Olkin measure confirmed good sampling adequacy, KMO = .72 and the determinant was .149 (greater than the recommended 0.00001; Field, 2009) suggesting that multicollinearity was not an issue with the data. Bartlett's test of sphericity χ^2 (36) = 164.25, $p < .001$, indicated that the correlations between items were large enough for PCA.

Based on Kaiser's criterion that all components with eigenvalues > 1 should be retained, a solution with three components was produced; however, this should not be taken as the sole method of determination (Costello & Osborne, 2005). Trials were conducted with two, three and

four components and the most appropriate model was the 3-component solution, which explained 60% of the variance. Inspection of the Scree Plot (Figure 2) revealed “break points” at only one component but also a slight inflection point at three. Because a 1-component solution would not produce meaningful results, the 3-component solution remained. Further, the religion subscale was removed from the final component solution due to high cross loadings across two components. The three components of the solution were named “Problem-Focussed Coping”, “Passive Coping” and “Help-Seeking Coping”; see Table 3 for a breakdown.

The data was less than optimal for exploratory factor analysis, as can be seen in Table 3, the internal reliability results for the passive coping (Cronbach’s α = .33) and help-seeking coping (Cronbach’s α = .30) components were inadequate. For this reason they were not included in the analysis. One limitation of the PCA results was that there were less than three items on the passive and help-seeking components, which goes against Costello and Osborne’s (2005) recommendation. The limited number of subscales retained following the removal of inadequate individual MSA values meant that there were few coping styles to group together to form meaningful components. Indeed, most of the coping styles that would be considered maladaptive were not included in the analysis. This may have been due to social desirability bias, people not responding truthfully to these questions. Further, there were 52% non-redundant residuals with absolute values greater than 0.05, suggesting there could be cause for concern over the fit of the model (Field, 2009).

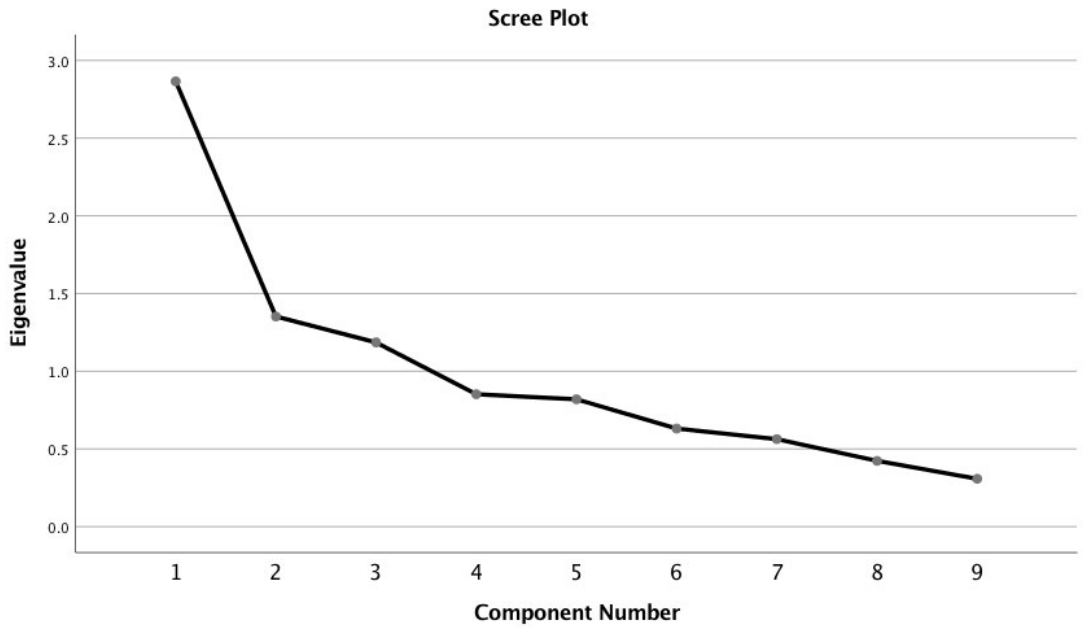

Figure 2 Brief-COPE Exploratory Factor Analysis Scree Plot

Table 3 Brief-COPE Scale Exploratory Factor Analysis Results

Items	Component 1	Component 2	Component 3
Active Coping	**.87**	-.06	.25
Positive Reframing	**.71**	.26	-.15
Behavioural Disengagement	**-.68**	-.05	.04
Planning	**.66**	.05	.04
Humour	-.06	**.81**	-.08
Acceptance	.19	**.60**	-.01
Instrumental Support	.31	.02	**.83**
Venting	-.43	-.11	**.65**
Eigenvalues	2.87	1.35	1.12
Explained Variance (%)	31.8	15.0	13.1
Cumulative Explained Variance (%)	31.8	46.9	60.0
Cronbach's α	.76	.33	.30

Note: Bold values load on factor at ≥.60; Component 1 = "*Problem-Focussed Coping*", Component 2 = "*Passive Coping*", Component 3 = "*Help-Seeking Coping"*

Table 4 Descriptive Statistics of Measures

Variable	Subscale	Items	*M* (*SD*)	Observed Range	Cronbach's α
BAS	Objective	10	2.56 (0.67)	1.11 – 3.89	.82
	Subjective	9	2.23 (0.58)	1.00 – 3.44	.75
CCRR		4	12.27 (2.65)	5 – 16	.72
SSQ6	Perceived availability	6	11.59 (7.70)	0 – 30	.91
	Satisfaction	6	27.75 (7.40)	6 – 36	.94
LOT-R		6	14.32 (4.00)	5 – 21	.83
COPE	Problem-Focussed	6	14.34 (4.71)	2 – 22	.76
CAS		6	6.30 (2.87)	0 – 14	.72
PAC		9	26.90 (9.12)	9 – 45	.91
DASS-21		21	26.92 (22.44)	0 – 112	.94

BAS = Burden Assessment Scale, CCRR = Quality of the Caregiver-Care Recipient Relationship, SSQ6 = Social Support Questionnaire – 6 item, LOT-R = Life Orientation Test Revised, COPE = Coping Orientation for Problems Experienced Inventory, CAS = Caregiver Ambivalence Scale, PAC = Positive Aspects of Caregiving, DASS-21 = Depressions, Anxiety and Stress Scales – 21 item.

Table 5 Pearson's Correlations Between Measures

Variable	CG Sex	Health	Hrs care	BAS obj	LOT-R	CCRR	SSQ quant	SSQ qual	BAS sub	Prob coping	CAS	PAC
CG sex[1]												
Health	.02											
Hrs care	-.01	.22*										
BAS obj	-.06	.31**	.24*									
LOT-R	-.01	-.32**	-.19	-.28**								
CCRR	.07	.04	.04	-.26*	.21*							
SSQ quant	-.26*	-.25*	-.10	-.30**	.42***	.19						
SSQ qual	-.15	-.31**	-.21*	-.41***	.48***	.22*	.52***					
BAS sub	-.09	.06	.06	.48***	-.36***	-.37***	-.16	-.31**				
Prob coping	-.07	-.33**	-.08	-.10	.44***	.38***	.27**	.33**	-.38***			
CAS	.00	.17	-.02	.30**	-.18	-.52***	-.04	-.20	.49***	-.41***		
PAC	.24*	-.26*	-.03	-.24*	.28**	.49***	.24*	.31**	-.39***	.52***	-.47***	
DASS	-.06	.33**	.26*	.47*	-.55***	-.13	-.36***	-.39***	.52***	-.40***	.26*	-.32**

Hrs care = Average hours of care provided per day, BAS obj = Objective subscale of Burden Assessment Scale, LOT-R = Life Orientation Test Revised, CCRR = Quality of the Caregiver-Care Recipient Relationship, SSQ quant = Perceived Availability subscale of Social Support Questionnaire – 6 item, SSQ qual = Satisfaction subscale of Social Support Questionnaire – 6 item, BAS sub = Subjective subscale of Burden Assessment Scale, Prob coping = Problem-Focussed Coping, CAS = Caregiver Ambivalence Scale, PAC = Positive Aspects of Caregiving, DASS = Depressions, Anxiety and Stress Scales – 21 item with Square Root Transformation
* $p < .05$, ** $p < .01$, *** $p < .001$

[1] Caregiver sex coding: female = 1, male = 2

3.3 Descriptive Statistics

Descriptive statistics for the measurement scales are shown in Table 4. Internal consistency scores, Cronbach's α, for all scales were good (> .70). Correlations between measures are shown in Table 5. Generally, correlations were in line with predictions although fewer *background variables* correlated with outcomes than predicted. Ambivalence was only weakly correlated with distress (r = .21). On the other hand, ambivalence and positive outcomes were moderately correlated (r = -.47). Positive outcomes and distress were negatively correlated (r = -.32).

3.4 Hierarchical Regression Model

Hierarchical regression was used to determine how well the variables predicted the outcomes of the study: positive, negative and ambivalent. The steps of the regression were determined from the stress and coping model (Mackay and Pakenham, 2012). In the first step, *background variables* were entered. However, only *background variables* that were correlated with the outcomes in simple correlation analyses were entered, see Table 6, Table 7 and Table 8 for details. The second step saw *coping resources*: relationship quality, optimism and social support subscales entered. In the third step, the subjective subscale of the BAS was entered as a measure of *appraisal* and in the fourth and final step the component extracted from the Brief-COPE exploratory factor analysis (see Section 3.2) was entered as a *coping style*.

The model predicted 55% of the variance in the distress outcome (DASS-21), 49% of positive aspects (PAC) and 47% of ambivalence (CAS). Inspection of the Durbin-Watson statistic for each model revealed no cause for concern over correlation of residuals between

observations i.e. it was between 1 and 3 (Field, 2009). The variation inflation values were well below 10 indicating that the models were not affected by multicollinearity of predictor variables. There were no Cook's D statistics greater than 1, indicating there were no overly influential data points (Field, 2009; Stevens, 2002). P-P plots, scatterplots and histograms of outputs were inspected for normality of residuals, homoscedasticity and linearity. The DASS-21 model failed to meet linearity and homoscedasticity assumptions and so a square root transformation of the dependent variable data only was applied. The square root transformation was deemed appropriate as it overcame the violation of assumptions and is applicable to zero values. The pattern of results within the model remained the same using the transformed data and there were no changes to the effect size (R^2). The standardised outputs from the transformed model are reported in the results (Table 6). The positive outcomes and ambivalence models both met assumption criteria and so no transformation was required.

3.4.1 Model 1 – Distress Outcome. In the model with DASS as the outcome (Table 6) *background variables* accounted for 28% of the variance, $F(3,82) = 10.40$, $p < .001$. Objective burden was the only significant predictor ($\beta = .39$). On Step 2 the introduction of *coping resources* accounted for an additional 16% of variance, $F(7,78) = 8.75$, $p < .001$. Optimism was a significant predictor ($\beta = -.42$), as was relationship quality ($\beta = .08$), the *background variable*, objective burden, remained significant in this step ($\beta = .33$). Introducing *appraisal* (subjective burden) in Step 3 explained a further 11% of variance in the model, $F(8,77) = 11.56$, $p < .001$. Subjective burden made a significant contribution ($\beta = .40$). Optimism remained a significant predictor ($\beta = -.34$) although objective burden and relationship quality did not. The introduction of *coping strategies* (step 4), did not contribute significant independent variance ($\Delta R^2 = .002$, $F(9,76) = 10.22$, n.s.). However, in this step relationship quality reached significance again. In

conclusion, two *coping resources* optimism, and relationship quality and subjective burden (β = -.33, 190 & .38, respectively) were independent predictors such that high distress was associated with low optimism, high quality CG-CR relationship and high subjective burden.

Table 6 Distress Hierarchical Regression Model (Transformed)

Variable	R^2	ΔR^2	SE (B)	β	*t*
Step 1 - Background Variables	.28	.28***			
Hours Care per Day			.02	.13	1.30
Physical Health			.23	.17	1.65
Objective Burden			.34	.39	3.84***
Step 2 - Coping Resources	.44	.16***			
Hours Care per Day			.02	.08	.83
Physical Health			.22	.04	.38
Objective Burden			.34	.33	3.30***
Optimism			.06	-.42	-3.95***
Relationship Quality			.08	.08	.87
Social Support Satisfaction			.03	-.06	-.48
Social Support Perceived Availability			.03	-.03	-.30
Step 3 - Appraisal	.55	.11***			
Hours Care per Day			.02	.09	1.14
Physical Health			.20	.07	.85
Objective Burden			.33	.19	1.91
Optimism			.06	-.34	-3.47***
Relationship Quality			.08	.18	2.04
Social Support Satisfaction			.03	-.02	-.22
Social Support Perceived Availability			.03	-.07	-.67
Subjective Burden			.37	.40	4.24***
Step 4 - Coping Strategies	.55	.002			
Hours Care per Day			.02	.09	1.14
Physical Health			.21	.06	.61
Objective Burden			.34	.20	1.98
Optimism			.06	-.32	-3.16**
Relationship Quality			.08	.19	2.11*
Social Support Satisfaction			.03	-.02	-.14
Social Support Perceived Availability			.03	-.07	-.67
Subjective Burden			.40	.38	3.72***
Problem-Focussed Coping			.05	-.06	-.56

*** $p < .001$, ** $p < .01$, * $p < .05$

3.4.2 Model 2 – Positive Outcomes. For positive outcomes (PAC), *background variables* explained 15% of variance ($F(3,87) = 5.05$, $p < .01$); the significant predictors were caregiver sex ($\beta = .23$) and physical health ($\beta = -.21$). Step 2, *coping resources*, explained an additional 25% of variance, $F(7,83) = 7.69$, $p < .001$. Relationship quality was a significant predictor ($\beta = .44$) and caregiver sex and physical health remained significant predictors ($\beta = .26$ & $-.22$, respectively). In the third step *appraisal* explained an additional 4% of variance, $F(8,82) = 7.68$, $p < .05$, subjective burden was a significant predictor ($\beta = -.23$). Finally, *coping strategies* were added in step 4, which explained an additional 5% of variance, $F(9,81) = 8.35$, $p < .01$. Thus, higher positive outcomes of caregiving were independently associated with being male, having high relationship quality and adapting problem-focussed coping styles ($\beta = .28$, $.29$ & $.30$, respectively).

Table 7 Positive Aspects of Caregiving Hierarchical Regression Model

Variable	R^2	ΔR^2	SE (B)	β	t
Step 1 - Background Variables	.15	.15**			
Caregiver Sex			2.21	.23	2.35*
Physical Health			.96	-.21	-2.01*
Objective Burden			1.42	-.16	-1.56
Step 2 - Coping Resources	.39	.25***			
Caregiver Sex			2.03	.26	2.91**
Physical Health			.89	-.22	-2.27*
Objective Burden			1.35	.05	.48
Optimism			.24	.02	.18
Relationship Quality			.32	.44	4.73***
Social Support Perceived Availability			.13	.11	.99
Social Support Satisfaction			.14	.14	1.27
Step 3 - Appraisal	.43	.04*			
Caregiver Sex			1.98	.25	2.85**
Physical Health			.87	-.25	-2.64**
Objective Burden			1.43	.14	1.32
Optimism			.24	-.04	-.40
Relationship Quality			.32	.39	4.18***
Social Support Perceived Availability			.12	.13	1.22
Social Support Satisfaction			.14	.12	1.11
Subjective Burden			1.64	-.23	-2.24*
Step 4 - Coping Strategies	.48	.05**			
Caregiver Sex			1.91	.28	3.23**
Physical Health			.90	-.15	-1.57
Objective Burden			1.44	.04	.41
Optimism			.23	-.10	-.97
Relationship Quality			.33	.29	3.11**
Social Support Perceived Availability			.12	.11	1.13
Social Support Satisfaction			.13	.10	.97
Subjective Burden			1.65	-.14	-1.34
Problem-Focussed Coping			.21	.30	2.87**

*** $p < .001$, ** $p < .01$, * $p < .05$

3.4.3 Model 3 – Ambivalence Outcome. *Background variables* explained 9% of the variance in ambivalence (CAS), $F(1,89) = 9.09$, $p < .01$. The only background variable included was objective burden ($\beta = .30$). The addition of *coping resources* at step 2 explained a further 23% of variance was $F(5,85) = 8.25$, $p < .001$ with the only significant predictor being relationship quality ($\beta = -.48$). *Appraisal* explained an additional 7% of variance, $F(6,84) = 9.10$, $p < .01$ with

subjective burden a significant predictor (β = .32) at step 3. In the final step, *coping strategies* explained an additional 8% of variance, $F(7,83) = 8.91$, $p < .05$. High Ambivalence was associated with low relationship quality, high subjective burden and low use of problem-focussed coping (β = -.34, .26 & -.23 respectively).

Table 8 Caregiver Ambivalence Hierarchical Regression Model

Variable	R^2	ΔR^2	SE (B)	β	t
Step 1 - Background Variables	.09	.09**			
Objective Burden			.43	.30	3.02**
Step 2 - Coping Resources	.33	.23***			
Objective Burden			.43	.19	1.86
Optimism			.08	-.05	-.52
Relationship Quality			.10	-.48	-5.12***
Social Support Perceived Availability			.04	.17	1.60
Social Support Satisfaction			.04	-.08	-.71
Step 3 - Appraisal	.39	.07**			
Objective Burden			.44	.07	.67
Optimism			.07	.02	.19
Relationship Quality			.10	-.40	-4.34***
Social Support Perceived Availability			.04	.13	1.29
Social Support Satisfaction			.04	-.06	-.57
Subjective Burden			.52	.32	3.05**
Step 4 - Coping Strategies	.43	.04*			
Objective Burden			.44	.12	1.19
Optimism			.07	.08	.78
Relationship Quality			.10	-.34	-3.66***
Social Support Perceived Availability			.04	.15	1.51
Social Support Satisfaction			.04	-.04	-.33
Subjective Burden			.52	.26	2.49*
Problem-Focussed Coping			.06	-.23	-2.26*

*** $p < .001$, ** $p < .01$, * $p < .05$

3.5 Power Analysis

Post hoc power analysis using G*Power 3.1.9.3 (Faul, Erdfelder, Buchner & Lang., 2009) showed that all three models were highly powered with $\alpha = 0.01$, $n = 91$, power > 0.99 for PAC and CAS models, and $\alpha = 0.01$, $n = 86$, power > 0.99 for the DASS-21 model.

4 Discussion

4.1 Overview of the Current Study

The current study investigated predictors of negative, positive and ambivalent outcomes for dementia caregivers. Analyses followed the stress and coping model put forward by Mackay and Pakenham (2012), which considers *background variables, coping resources, appraisal* and *coping strategies* as the variables that predict adjustment outcomes. The hierarchical regression models successfully predicted a large amount of variance in the outcomes i.e. distress (R^2 = .55), positive aspects (R^2 = .48) and ambivalence (R^2 = .43). All steps of the models made significant contributions to the outcomes, with the exception of *coping strategies* on distress. Generally speaking there were fewer predictors of the outcomes than was proposed based on the existing literature. Particularly, social support contributed no significant independent variance in any of the outcome variables and few *background variables* were significant predictors (see Figure 3 for summary). Relationship quality had a positive relationship with distress whereas a negative relationship was predicted.

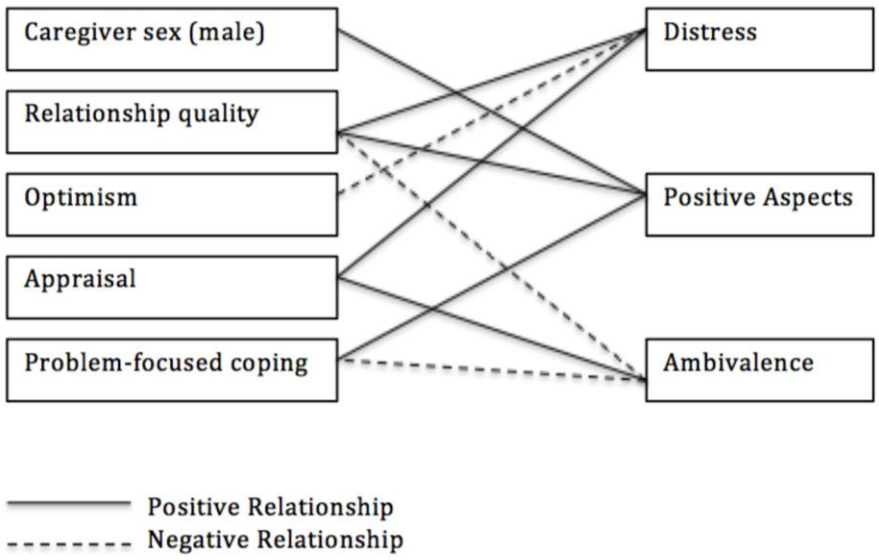

Figure 3 Relationships between Predictor Variables and Outcomes

4.2 Predictors of Distress

No *background variables* made significant independent contributions to the outcome of distress after entering the *coping resources, appraisal* and *coping strategies* variables. Previous studies have highlighted relationships between *background variables* with negative outcomes, although, most relationships were small and the studies were inconsistent (Pinquart & Sörensen, 2006; Gonzalez-Salvador et al., 1999). Exceptions to this are objective burden and self-rated physical health, both of which were common themes in the negative outcomes research (Schulz et al., 1995). As such, it is surprising that objective burden and physical health have not predicted distress. In this study the *coping resources*, *appraisal* and *coping strategies* variables have accounted for their variance. Objective burden was a significant predictor until *appraisal* was entered; therefore, it appears that the variance explained by objective burden was mediated by *appraisal*. *Appraisal* had a positive relationship with distress, indicating that positive appraisal of the situation is an important protective factor against distress. Of the *coping resources*, optimism and relationship quality significantly predicted distress. Optimistic personality traits are important in facilitating well-being in many situations (Scheier & Carver, 1985) which extends to the role of dementia caregiving, according to this study. This study showed that better relationship quality was associated with more distress in the caregiver; the prediction was small but significant. One might expect the opposite to be true, intuitively, and this also the trend in previous caregiving literature (e.g. Quinn, Clare, McGuinness & Woods, 2012; Mackay & Pakenham, 2012). One explanation for the finding is that the stronger the relationship between the CG and CR, the more difficult it is for the CG to watch the disease take its toll on their loved one and the more distressing it might be to lose them. *Coping strategies*, although limited in this study, did not make a significant contribution to distress, suggesting that a person's resources and

appraisal of the situation are more influential on their level of distress than the strategies they typically employ to cope with it.

4.3 Predictors of Positive Outcomes

One main purpose of the study was to address the lack of consistency in assessing predictors of positive outcomes in dementia caregivers. An appropriate and comprehensive model was used with an outcome measure that analysed a wide scope of positive aspects. The only background variable to make a significant contribution to the positive outcomes model was caregiver sex; males experienced higher levels of positive outcomes. The literature has been mixed and inconclusive on sex differences (Sharma et al., 2016). Kinney & Stephens (1989) found the opposite effect to this study; however, more recent studies have supported the finding that male caregivers experience more satisfaction in elderly care situations (Ekwall & Hallberg, 2007; López, López-Arrieta & Crespo, 2005). It has been suggested that caregiving in men motivates growth and expands on their life, perhaps because they have had less exposure to caring in their past due to stereotypical gender roles (Ekwall & Hallberg, 2007). Although sex is not a manipulable variable it could be explored as to why males experience more positive outcomes and how we can integrate this to improve outcomes for female caregivers. Relationship quality was the only significant predictor from the *coping resources*. For positive outcomes relationship quality influence was in the direction that was expected, such that better relationship quality predicted more positive outcomes. *Appraisal* had no independent effect on the positive outcomes. Despite inconsistencies in the literature, this study found that problem-focussed coping styles resulted in more positive outcomes. We cannot infer causality, however, it would

seem that coping styles aimed at addressing and overcoming the problem should be encouraged in caregivers.

4.4 Predictors of Ambivalence

The second key purpose of the study was to address the lack of research directed at ambivalence predictors in caregivers. This study identified three variables (relationship quality, subjective burden and problem-focussed coping) that contribute to ambivalence in dementia caregivers using an appropriate and comprehensive model of stress and coping. These variables should be considered in future caregiver research and interventions. No *background variables* were significant predictors of ambivalence despite research suggesting that parent-child dyads, younger CGs and more time spent together would lead to higher ambivalence (Fingerman, 2006; Losada et al., 2017). The results from the current study revealed a negative relationship between relationship quality and ambivalence. This indicates that the closer the CG feels to the CR, the less ambivalent they are about the situation. *Appraisal* also significantly predicted ambivalence. The more negatively a person appraised the situation, the more ambivalence they experienced. Causal direction of this relationship cannot be assumed so it is not known whether negative appraisal leads to ambivalence or higher ambivalence leads to negative appraisal. Lastly, problem-focussed coping was negatively related with ambivalence, suggesting that taking action to address potential stressors can reduce the ambivalence experienced.

4.5 Relationships Between Outcomes

Ambivalence is the simultaneous co-occurrence of high positive and high negative affect (Cacioppo et al., 1997). By this definition it was expected that ambivalence would be positively

correlated with distress and positive outcomes. Instead, ambivalence was negatively correlated with positive outcomes. It is theorized that this occurred because the positive outcomes were personal rather than based on affect towards the CR. Combined with the weak positive correlation between ambivalence and distress, the findings suggests that ambivalence is a negative experience. Negative and positive outcomes were only weakly correlated, they had different predictors and better relationship quality predicted both negative and positive outcomes, supporting the literature that they are independent variates, as opposed to ends of one continuum (Cacioppo et al., 1997).

4.6 Methodological Strengths & Implications

The methodological basis of this study was grounded in the well-established theory of stress and coping, used in many caregiving studies (Lazarus & Folkman, 1984; Mackay & Pakenham, 2012; Kramer, 1997). These made it comparable with other findings and ensured that the appropriate concepts were considered. A particular strength of the stress and coping model used was its comprehensiveness and the thorough consideration of *background variables* (Mackay & Pakenham, 2012). Further, the use of psychometrically sound and previously validated self-report measures allowed for confidence in the results and ensured internal reliability within scales. The PAC measure (Tarlow et al., 2004) used to assess positive aspects had excellent internal consistency (Cronbach's $\alpha = .91$) and measured various positive aspects of the caregiving experience (e.g. self-efficacy, relationships and outlook on life). The selected outcomes (distress, positive aspects and ambivalence) covered a wide range of caregiving variables allowing for a holistic view of the experience. The study took a unique standpoint on

the caregiving experience by assessing positive aspects and ambivalence as outcomes rather than mediators to distress.

This study identified some key predictors of negative, positive and ambivalent outcomes in dementia caregivers. These findings can further inform the literature around cognitive, interpersonal and behavioural processes that are beneficial to the caregiver and can encourage relevant support. This study found quality of relationship and problem-focussed coping to be particularly salient and it is recommended that interventions for dementia caregivers focus on these aspects as well as reducing subjective burden and increasing optimism. Being the first study to look at predictors of ambivalence this study should open up avenues for future research to further our understanding of this concept in caregivers.

4.7 Limitations

This was a cross-sectional study and so lacks insight into the changing nature of the caregiving experience and adjustment outcomes over time. Therefore, it cannot provide the same depth of the experience that a longitudinal study could. Although the variable that measured time spent caregiving (in increments: *less than 6 months, 6 months to 1 year, 1 – 5 years, 6 – 10 years and 10+ years*) had no correlation with the outcomes, this may not account for the constantly changing experience of the caregiver and the different stages of decline for individuals. The cross-sectional design also limits the inferences we can make regarding causal direction.

The study would have benefited from a larger sample size. Despite having sufficient power in the regression models a larger sample size would have allowed a structural equation

modelling approach including all three outcomes in a single analysis. A larger sample size would have also made components from the exploratory factor analysis of the Brief-COPE scale (Carver, 1997) more interpretable. As discussed in Section 3.2, the exploratory factor analysis was unsuccessful in producing sensible components with an appropriate number of subscales in each, most likely due to the number of participants.

The study participants were more highly educated than the general population of Australia. This is likely due to the fact that caregivers would need to be familiar with computers and interested in psychological studies to participate. It is not expected that education level would impact on the stress and coping processes and, in-fact, in this study education was not correlated to any other variables; however this could limit the generalizability of the findings. Self-selection to volunteer in the study may also affect the generalizability of the results. Caregivers who experience higher burden or distress may be less likely to participate in a study of this kind.

4.8 Future Research

Future research to extend this study would involve qualitatively analysing the responses to the open-ended question. This would allow for a more in-depth understanding of the themes that are expressed by caregivers about caring for a loved one with dementia. This would be particularly salient in regards to identifying needs for caregiver support and is highly recommended.

As discussed in the limitations section, and in previous caregiver studies (e.g. Crellin, Orrell, McDermott & Charlesworth, 2014), a longitudinal study of the outcome variables would be beneficial to observe how the change in the illness over time affects the outcomes for the caregiver. This is especially pertinent in dementia caregivers as the condition causes gradual decline in CR health, eventually leading to death. As such, the strain would assumedly increase over time to then be compounded with the anticipatory grief of losing their loved one (Holley & Mast, 2009).

Due to the inconsistencies in the positive outcomes literature around research designs, operational definitions of positive outcomes and measurement scales, further studies using the current model and Positive Aspects of Caregiving scale (Tarlow et al., 2004) are encouraged. This should be conducted on larger and more diverse samples of dementia caregivers, and other caregivers more generally, in order to make comparisons between groups and further the knowledge base in this area.

4.9 Conclusions

As the demand for dementia caregivers increases, the processes through which they experience negative, positive and ambivalent outcomes are of utmost importance. The results of the present study make an important contribution to understanding the predictors of outcomes. The transactional model of stress and coping was found to be applicable to dementia caregivers and is supported for use in this group. The findings have implications for future research, particularly for ambivalence and positive outcomes in caregivers. A longitudinal study of the

outcomes is recommended along with a qualitative analysis of the open-ended responses from this study.

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World Health Organisation. (2012). *Dementia: a public health priority.* Retrieved from http://www.who.int/mental_health/publications/dementia_report_2012/en/

World Health Organisation (2016). Mental and behavioural disorders. In *International Statistical Classification of Diseases and Related Health Problems 10th Revision*. Retrieved from http://apps.who.int/classifications/icd10/browse/2016/en#/F00

Zarit, S., & Talley, R. (2013). *Caregiving for Alzheimer's disease and related disorders*. New York, NY: Springer.

Appendix 1 – Letter to Organisations

My name is Andrea Richardson and I am a psychology honours student at The University of Adelaide. I am completing a thesis under the supervision of Dr Lynn Ward, exploring the positive, negative and ambivalent outcomes of providing care for loved ones with dementia. We are currently identifying organisations that work with loved ones of people with dementia to help locate potential participants for our study. Your time and assistance would be greatly appreciated by the researchers.

Participation will involve caregivers completing an online survey that has been approved by the University of Adelaide's Human Research Ethics Committee. The survey data will allow us to explore the relationships between factors such as coping strategies, ambivalence and positive outcomes.

Having identified your organisation online as one that may reach potential participants, we wish to inquire whether you would be willing and able to make our research project known to your members or other relevant organisations. This would involve circulating the attached invitation letter to potential participants by means you deem appropriate i.e. newsletter, emails, Facebook, website, in office etc. The invitation letter will include a link for the participants to then become involved voluntarily. Additional information and details of ethical clearance can be provided if you desire. The invitation letter, as attached, will make it clear that the identity and contact details of those invited to participate will not be provided to the researchers. If you wish to include an introduction to the study you may use the draft provided if preferred (attached).

If you are able, please forward this email to other organisations who may have contact with caregivers of people with dementia.

If you would like further information please do not hesitate to contact me [redacted]

We are so grateful for any help you can provide.

Thank you in advance and I look forward to hearing from you soon,
Andrea Richardson

Appendix 2 – Organisations Contact List

Name of organisation	Email contact	Status	Sent on
Abel Tasman	info@abeltasman.com.au	Sent	27/5/18
ADS Care	info@adscare.com.au	Sent	27/5/18
Aged and Community Services Australia	acsacommunications@acsa.asn.au	Sent	27/5/18
Aged Care Guide	info@dps.com.au	Sent	27/5/18
Aged Care Online	media@agedcareonline.com.au	Sent	27/5/18
Ageing and Aged Care (gov)	dacs@health.gov.au	Could not help	27/5/18
Alzheimer's Australia SA	sa.admin@alzheimers.org.au	Sent	27/5/18
Alzheimer's WA	support@alzheimerswa.org.au	Sent	27/5/18
Alzheimers Queensland (QLD)	enquiries@alzqld.org.au	Sent	27/5/18
Anglican Care	admin@anglicancare.com.au	Sent	27/5/18
Australian Aged Care Quality Agency	national@aacqa.gov.au	Sent	27/5/18
Baptist Care Home Services Canberra	ask@baptistcare.org.au	Sent	27/5/18
Care Page	hello@carepage.com.au	Sent	27/5/18
Carers ACT	communications@carersact.org.au colleen.sheen@carersact.org.au	Sent	27/5/18
Carers Australia	caa@carersaustralia.com.au	Sent	27/5/18
Carers NSW	research@carersnsw.org.au	Asked for further information, provided.	27/5/18
Carers NT (NT)	carersnt@carersnt.asn.au	Sent	27/5/18
Carers NT (NT)	Public.relations@carersnt.asn.au		27/5/18
Carers Queensland (QLD)	pgourley@carersqld.asn.au	Sent	27/5/18
Carers SA	info@carers-sa.asn.au	Sent	27/5/18
Carers SA	david.militz@carers-sa.asn.au	Sent	27/5/18
Carers TAS	intake@carerstasmania.org	Have carer burden but will try their best	27/5/18
Carers VIC	reception@carersvictoria.org.au	Sent	27/5/18
Carers Victoria	anne.muldowney@carersvictoria.org.au	Unable to help	27/5/18
Carers WA	info@carerswa.asn.au	Asked for further information, provided. Circulated via facebook and e-newsletter	27/5/18
Carers WA	ciep@carerswa.asn.au	Sent	27/5/18
CarersNSW	contact@carersnsw.org.au	Sent	27/5/18
Carrington	info@carringtoncare.com.au	Unable to help	27/5/18
Catholic Healthcare	mediaenquiries@chcs.com.au	Sent	27/5/18
Catholic Healthcare	enquiries@chcs.com.au	Sent	27/5/18
Community Visitor Scheme		Made some suggestions but could not circulate	27/5/18
Dementia 2017	info@dementia2017.org	Old email address	27/5/18
Dementia Australia ACT	act.admin@dementia.org.au	Sent	27/5/18

Dementia Australia Barton	nat.admin@dementia.org.au	Sent	27/5/18
Dementia Australia Cairns	qld.cairns@dementia.org.au	Sent	27/5/18
Dementia Australia Far South Coast	nsw.farsouthcoast@dementia.org.au	Sent	27/5/18
Dementia Australia Maryborough	qld.maryborough@dementia.org.au	Sent	27/5/18
Dementia Australia Mid North Coast	nsw.midnorthcoast@dementia.org.au	Forwarded on to manager	27/5/18
Dementia Australia Newcastle	nsw.hunter@dementia.org.au	Sent	27/5/18
Dementia Australia NSW	nsw.admin@dementia.org.au	Sent	27/5/18
Dementia Australia NT	nt.admin.d@dementia.org.au	Sent	27/5/18
Dementia Australia QLD	qld.general@dementia.org.au	Will circulate to carers in meetings	27/5/18
Dementia Australia Research	research@dementia.org.au	Shared in newsletter and facebook and research page - definitely on research page, can't see on FB	27/5/18
Dementia Australia Rockhampton	qld.rockhampton@dementia.org.au	Sent	27/5/18
Dementia Australia SA	sa.admin@dementia.org.au	Responded, asked that I share on the website and will disseminate among network and possibly publish in media	27/5/18
Dementia Australia Sutherland	nsw.southsydney@dementia.org.au	Sent	27/5/18
Dementia Australia TAS	tas.admin@dementia.org.au	Sent	27/5/18
Dementia Australia Toowoomba	qld.toowoomba@dementia.org.au	Sent	27/5/18
Dementia Australia Townsville	qld.townsville@dementia.org.au	Sent	27/5/18
Dementia Australia VIC	vic.admin@dementia.org.au	Sent	27/5/18
Dementia Australia Wingecarribee	nsw.wingecarribee@dementia.org.au	Sent	27/5/18
Dementia Caring Australia (National)	info@dementiacaring.com.au	Sent	27/5/18
Dial an Angel	administration@dialanangel.com	Sent	27/5/18
Elder Care (SA)	admin.headoffice@eldercare.net.au	Sent	27/5/18
Evergreen Life Care	info@evergreenlifecare.org.au	Sent	27/5/18
Focus Care	enquiries@focuscare.com.au	Sent	27/5/18
Health Direct (National)	nhsd@healthdirect.org.au	Directed me to a dataset	27/5/18
Home Care Assistance (QLD)	mlye@homecareassistance.com	Sent	27/5/18
Home Care Plus	info@homecareplus.asn.au	Sent	27/5/18
Home Instead	lowernorthshore@hiscneutralbay.com.au	Sent	27/5/18
Home Instead (WA)	perth@homeinsteadwa.com.au	Sent	27/5/18
Informa	enquiries@informa.com.au	Sent	27/5/18
Just Better Care	mailrp@justbettercare.com	Sent	27/5/18
Kin Care	mail@kincare.com.au	Sent	27/5/18

Life Circle	info@lifecircle.org.au	Sent	27/5/18
Oxley Home Care	admin@oxleyhomecare.com.au	Sent	27/5/18
Ozcare (QLD)	Karen.constant@ozcare.org.au	Sent	27/5/18
Red Cross	contactus@redcross.org.au	Sent	27/5/18
Red Cross ACT	actinfo@redcross.org.au	Sent	27/5/18
Red Cross Kimberley	kimberleyteam@redcross.org.au	Sent	27/5/18
Red Cross Narooma	narooma@redcross.org.au	Sent	27/5/18
Red Cross NSW	nswinfo@redcross.org.au	Sent	27/5/18
Red Cross NT	ntinfo@redcross.org.au	Sent	27/5/18
Red Cross QLD	qldredcross@redcross.org.au	Will circulate	27/5/18
Red Cross SA	sainfo@redcross.org.au	Sent	27/5/18
Red Cross TAS	tas@redcross.org.au	Sent	27/5/18
Red Cross VIC	vicinfo@redcross.org.au	Sent	27/5/18
Red Cross WA	wainfo@redcross.org.au	Sent	27/5/18
Resthaven (SA)	headoffice@resthaven.asn.au	Unable to help	27/5/18
Right at Home	info@rightathome.com.au	Sent	27/5/18
Rise Community Network	contactAC@risenetwork.com.au	Sent	27/5/18
Rise Community Network	contactCG@risenetwork.com.au	Sent	27/5/18
Rise Community Network	contact@risenetwork.com.au	Sent	27/5/18
Southern Cross Care (WA)	info@scrosswa.org.au	Sent	27/5/18
St Basil's Home Care	enquiries@stbasils.org.au	Sent	27/5/18
St Simeon Healthcare	homecare@stsimeon.org.au	Sent	27/5/18
The Aged Care Rights Service	tars@tars.com.au	Sent	27/5/18
Uniting Home Care ACT	ask@uniting.org	Unable to help	27/5/18
Warrigal	warrigal@warrigal.com.au	Sent	27/5/18
Wendy's Home Care	admin@wendyshome.com.au	Sent	27/5/18
COTA	cota@cota.org.au	Forwarded on to manager	6/6/18
Seniors Newspaper	classifieds@apn.com.au	Sent	6/6/18
The Senior Newsletter Editor - Cheryl Field	edit@thesenior.com.au	Sent	6/6/18
The Senior Newsletter VIC office - Sue Miceli	smiceli@thesenior.com.au	Sent	6/6/18
Your Life Choices newsletter	admin@YourLifeChoices.com.au	Sent	6/6/18
National Seniors Newsletter	general@nationalseniors.com.au	$2000 per month - could not help	7/6/18
Ages Rights Advocacy Service	aras@agedrights.asn.au	Sent	19/6/18
Anglicare	admin@anglicaresa.com.au	Sent	19/6/18
Minda Aged Care	disability.choices@minda.asn.au	Sent	19/6/18
Southern Cross Care (SA and NT)	enquiry@southerncrosscare.com.au	Sent 21/6	21/6/18
Young Carers		Sent	21/6/18
	editor@nsaalbanycreek.org.au		21/6/18
	garybyron@optusnet.com.au	Has circulated	21/6/18
	ruth.jack@bigpond.com		21/6/18
	nsaaspley@hotmail.com		21/6/18
	zois16@iprimus.com.au		21/6/18
	info@berwicknsa.org.au		21/6/18

	egs41@y7mail.com		21/6/18
	h.d.willey@bigpond.com	Had no dementia carers but forwarded on	21/6/18
	cairns.tropical.nsa@gmail.com		21/6/18
	nsacalamvale@gmail.com		21/6/18
	nsacanberrasouth@gmail.com	Has forwarded on	21/6/18
	capricornianationalseniorsaust@gmail.com		21/6/18
	cherubu@bigpond.com		21/6/18
	gallypat@westnet.com.au		21/6/18
	clevelandnsa1@bigpond.com		21/6/18
	nsdandenong@gmail.com		21/6/18
	kpar8794@bigpond.net.au		21/6/18
	nsaforestlakesec@gmail.com		21/6/18
	nsafrankston@gmail.com		21/6/18
	greensboroughnationalseniors@gmail.com		21/6/18
	carolines_gong@bigpond.com		21/6/18
	nsa.joondalup@gmail.com		21/6/18
	klemzignationalseniors@gmail.com		21/6/18
	johngiles@aapt.net.au		21/6/18
	asom9346@bigpond.net.au		21/6/18
	scato@ozemail.com.au		21/6/18
	nsamaroondah@gmail.com		21/6/18
	lamimoore@gmail.com		21/6/18
	jillfalla@hotmail.com		21/6/18
	nsanewfarm@hotmail.com.au		21/6/18
	paradisepointnationalseniorsau@gmail.com		21/6/18
	tmartn@optusnet.com.au		21/6/18
	information@nsapenrith.com		21/6/18
	rosebudnsa@gmail.com		21/6/18
	skinut99@optusnet.com.au		21/6/18
	helen88@iinet.net.au		21/6/18
	maybruce@bigpond.com		21/6/18
	jj.densley@bigpond.com		21/6/18
	dawnbw7@yahoo.com.au		21/6/18
	hazken59@gmail.com		21/6/18
	wynnieone56@bigpond.com		21/6/18
	anndemaine1@bigpond.com		21/6/18
act gov veterans and seniors	communityparticipation@act.gov.au	Sent	25/6/18
Australian Ageing Agenda	advertise@australianageingagenda.com.au	Sent	25/6/18
Australian Retired Persons Association	info@arpasa.asn.au	Sent	25/6/18
Bethanie	info@bethanie.com.au.	Sent	25/6/18
Golden Carers	support@goldencarers.com	Could not help - only allow members to share	25/6/18
Golden Glow Nursing	info@goldenglownursing.com.au	Referred me to Carers NT	25/6/18
Hender Care	hello@hendercare.com.au	Sent	25/6/18
Little Bay Coast Centre	manager@coastcentre.org.au	Will circulate	25/6/18
Mental Health Carers	contact.us@mentalhealthcarersaustralia.org.au	Sent	25/6/18
Northern Carers Network	office@ncnw.org.au	Sent	25/6/18
Seniors card newsletter	business@seniorscard.nsw.gov.au	Will circulate in newsletter 6/7/18	25/6/18
Seniors Enquiry Line	sel@uccommunity.org.au	Sent	25/6/18
Seniors information service	information@seniors.asn.au	Has circulated on Facebook and will attempt to get in newsletter	25/6/18
Silver Chain	media@silverchain.org.au	Sent	25/6/18
the Australian Journal of Dementia Care	kerry@australianjdc.com	Forwarded on to carers group	25/6/18
Carer Gateway	Called	Cannot help - gov organisation	26/6/18

Mental Illness Fellowship of Australia	mifa@mifa.org.au	Sent	26/6/18
Carer Support	enquiries@carersupport.org.au	Will circulate via Facebook	26/6/18
Carer Support Media	media@carersupport.org.au	Sent	26/6/18
Lifeline	media@lifeline.org.au	Sent	26/6/18
The Carers Place	sent via facebook and contact us page		26/6/18
Carers and Disability Link	barossa@cadl.support	Sent	30/5/18

Coffin Bay Sun Newsletter	coffinbaysun@gmail.com	Will put in August newsletter	5/7/18
Cummins Connection Newsletter	cdec@dclep.sa.gov.au	Sent	5/7/18
Seniors Card SA	seniorscard@sa.gov.au	$300 for an add in the newsletter	7/7/18
Seniors Card VIC	seniorscard@dhhs.vic.gov.au	Can not circulate	7/7/18
Seniors Card WA	info@seniorscard.wa.gov.au	Sent	7/7/18

Sent to all the below National Seniors Local Representatives		21/6/18
Local councils		
	city@cityofadelaide.com.au	
	mail@ahc.sa.gov.au	Will email out to contacts
	info@apc.sa.gov.au	
	alex@alexandrina.sa.gov.au	
	barossa@barossa.sa.gov.au	
	barunga@barungawest.sa.gov.au	
	bbc@berribarmera.sa.gov.au	
	burnside@burnside.sa.gov.au	
	cityof@campbelltown.sa.gov.au	
	council@ceduna.sa.gov.au	
	council@charlessturt.sa.gov.au	
	admin@cgvc.sa.gov.au	
	council@cleve.sa.gov.au	
	dccp@cpcouncil.sa.gov.au	
	council@coorong.sa.gov.au	
	info@coppercoast.sa.gov.au	
	council@frc.sa.gov.au	
	council@franklinharbour.sa.gov.au	
	council@gawler.sa.gov.au	
	council@goyder.sa.gov.au	
	info@dcgrant.sa.gov.au	
	mail@holdfast.sa.gov.au	
	kicouncil@kicouncil.sa.gov.au	
	council@dckem.sa.gov.au	
	council@kimba.sa.gov.au	
	info@kingstondc.sa.gov.au	
	light@light.sa.gov.au	
	lgasa@lga.sa.gov.au	
	mail@dclep.sa.gov.au	Passed on to local groups and suggested newsletter contacts
	council@loxtonwaikerie.sa.gov.au	
	maratjar@bigpond.net.au	
	council@marion.sa.gov.au	
	postbox@mid-murray.sa.gov.au	
	mitcham@mitchamcouncil.sa.gov.au	Forwarded to community wellbeing team
	council@mountbarker.sa.gov.au	
	city@mountgambier.sa.gov.au	
	postmaster@mtr.sa.gov.au	
	council@murraybridge.sa.gov.au	will circulate in newsletter
	council@nlc.sa.gov.au	
	nepabunnacommunity@bigpond.com	
	ceo@nacouncil.sa.gov.au	
	townhall@npsp.sa.gov.au	
	mail@onkaparinga.sa.gov.au	
	council@orroroo.sa.gov.au	
	oca@sa.gov.au	
	council@peterborough.sa.gov.au	

playford@playford.sa.gov.au	
admin@portaugusta.sa.gov.au	
plcc@plcc.sa.gov.au	
council@pirie.sa.gov.au	
admin@prospect.sa.gov.au	
council@renmarkparinga.sa.gov.au	
council@robe.sa.gov.au	
roxby@roxbycouncil.com.au	
city@salisbury.sa.gov.au	
council@southernmallee.sa.gov.au	
dcstreaky@streakybay.sa.gov.au	
office@tatiara.sa.gov.au	
customerservice@cttg.sa.gov.au	
dctumby@tumbybay.sa.gov.au	
pobox1@unley.sa.gov.au	
localgov@victor.sa.gov.au	
admin@wakefieldrc.sa.gov.au	
walkerville@walkerville.sa.gov.au	Will post in library
council@wattlerange.sa.gov.au	
csu@wtcc.sa.gov.au	
council@whyalla.sa.gov.au	
admin@wudinna.sa.gov.au	
council@yankalilla.sa.gov.au	
admin@yorke.sa.gov.au	

Appendix 3 – Invitation Letter

To whom it may concern,

You are invited to participate in a research project being conducted at the University of Adelaide by Psychology Honours student, Andrea Richardson. The following information is provided for you to consider before you decide whether to take part.

What is the research project about?

The project is about caregivers of people with dementia. We hope to gain a better understanding of their experiences and what impacts upon positive and negative outcomes for caregivers. Also, we are interested in the way that people can have positive and negative feelings towards a person at the same time.

Why am I being invited to participate?

You have been invited because you may be a caregiver to someone with dementia. Your identity and contact details have NOT been provided to the researchers. If you know other caregivers of people with dementia, you may pass on this invitation.

Who can participate?

To participate in this study you and the person you care for must be over the age of 18, and you must be able to understand written English. The person you care for must have a diagnosis of dementia and you must be the primary caregiver, particularly you must be:

- Providing care for at least 1 hour each day, and
- Providing primary care for at least 3 months

What does the project involve?

You are invited to complete an anonymous online survey which will take approximately 20-30

minutes to complete. Alternatively, you may contact the researchers and request a paper copy of the survey to complete and return. You will be provided a reply paid envelope.

What are the potential benefits of this project?

We hope that the results of this study will contribute to our understanding of the positive benefits of the caregiving role and the coping styles, experiences and outcomes of those providing care for loved ones with dementia.

Are there any risks associated with participating?

There are no foreseeable risks associated with this project.

What will happen with my information?

Your information will remain entirely confidential and you will not be personally identifiable.

Further information is provided before participating in the survey.

Survey Link:

[redacted]

Appendix 4 – Flyer

THE UNIVERSITY of ADELAIDE

Research Participants Wanted

We are looking for caregivers of loved ones with Dementia to complete a survey

We hope that our study will make a contribution to our understanding of the positive outcomes for caregivers. We are also looking at negative outcomes and ambivalence in caregivers. Your help would be greatly appreciated.

Who can participate?
You must be providing care for a loved one with dementia, over 18 years' old and able to understand written English

What is involved?
The project involves completing a survey, which can be done online by following this link: [redacted]
You may also request a paper copy with a reply paid envelope by contacting the researchers below.

How can I get more information?
Please see the information sheet by following the link or contact the researchers below.

Researchers
[redacted]

Human Research Ethics Committee Approval Number [redacted]

Appendix 5 – Survey

Positive, Negative and Ambivalent Feelings: Potential Outcomes of Providing Care for People with Dementia

Participant Information

Human Research Ethics Committee Approval Number: H-2018-098

Welcome! And thank you for your interest in our survey.

You are invited to participate in a research project being conducted at the University of Adelaide by Psychology Honours student, Andrea Richardson. The following information is provided for you to consider before you decide whether to take part.

If you wish to complete this study by paper copy you may contact the researchers and request a copy to complete and return. You will be provided a reply paid envelope.

What is the research project about?
The project is about caregivers of people with dementia. We hope to gain a better understanding of their experiences and what impacts upon positive and negative outcomes for caregivers. These outcomes include things such as improved relationships, a sense of purpose, stress, and ambivalence (simultaneously feeling positive and negative towards your care receiver). The factors we are considering include details about you and your care receiver, your caring situation and your coping styles.

Who is undertaking the project?
This project is being conducted by [redacted]. This research will form the basis for the degree of Honours in Psychology at the University of Adelaide under the supervision of [redacted]

Why have I been invited to participate?
You have been invited because you may be a caregiver to someone with dementia. Organisations involved with dementia were approached to invite their members and/or contacts to participate. Your identity and contact details have NOT been provided to the researchers.

Who can participate?
To participate in this study you and the person you care for must be over the age of 18, and you must be able to understand written English. The person you care for must have a diagnosis of dementia and you must be the primary caregiver, particularly you must be:

- **Providing care for at least 1 hour each day, and**
- **Providing primary care for at least 3 months**

What does the project involve?
You are invited to complete an anonymous online survey which will take approximately 20-30 minutes to complete. The survey asks questions about aspects of your caregiving experience such as details about you and your care receiver, your coping strategies, and your feelings.

What are the potential benefits of the research project?
We hope that the results of this study will contribute to our understanding of the benefits of the caregiving role and the experiences of those providing care for loved ones with dementia. This information may help to direct further research and support in this field. However, there will be no immediate benefits to you as the participant.

Are there any risks associated with participating in this project?
There are no foreseeable risks associated with this project, but if you do find any of the questions distressing you can discontinue the survey at any time. The questions may address sensitive and personal issues for yourself, including questions about burden, how you cope and negative feelings that you experience. Counselling support can be made available by contacting your local GP, Lifeline (13 11 14, available 24 hours), Mind Carer Helpline (1300 554 660) or Carers Australia (1800 242 636). This information will also be available at the end of the survey.

Can I withdraw from the project?
Participation in this project is completely voluntary. If you agree to participate, you can withdraw from the study at any time, up until the submission of the survey.

Positive, Negative and Ambivalent Feelings: Potential Outcomes of Providing Care for People with Dementia

* 1. What is your age?

* 2. Please select your sex

- Female
- Male

* 3. In which State/Territory do you live?

- QLD
- NSW
- ACT
- VIC
- TAS
- SA
- WA
- NT

* 4. What relationship do you have with the person you care for? I am their:

- Parent
- Spouse/partner
- Sibling
- Son/daughter
- Other (please specify)

* 5. What is the sex of the person you care for?

- Female
- Male

* 6. What is the age of the person you care for?

* 7. How would you rate your physical health?

- ◯ Excellent
- ◯ Very good
- ◯ Good
- ◯ Fair
- ◯ Poor

* 8. What type of dementia was the person you care for diagnosed with?

- ◯ Alzheimer's disease
- ◯ Vascular dementia
- ◯ Dementia with Lewy bodies
- ◯ Mixed dementia
- ◯ Frontotemporal dementia
- ◯ Creutzfeldt-Jakob disease
- ◯ Normal pressure hydrocephalus
- ◯ Parkinson's disease
- ◯ Huntington's disease
- ◯ Not sure
- ◯ Other (please specify)

* 9. What is the highest level of education you have completed?

- ◯ Year 9 or below
- ◯ Secondary school/Certificate I or II
- ◯ Certificate III or IV
- ◯ Diploma/advanced diploma
- ◯ Bachelor or above
- ◯ Choose not to answer

* 10. Which of the following best describes your employment?

- ◯ Full time
- ◯ Part time
- ◯ Casual
- ◯ None

* 11. On average, how many hours of care do you provide per day?

* 12. Approximately, how long have you been providing care for your loved one with dementia?

- ◯ Less than 6 months
- ◯ 6 months to 1 year
- ◯ 1-5 years
- ◯ 6-10 years
- ◯ Longer than 10 years

* 13. Which ethnicity do you most identify with? You may choose more than one

- ☐ Australian
- ☐ Aboriginal or Torres Strait Islander
- ☐ Asian
- ☐ New Zealander
- ☐ British/Irish
- ☐ European
- ☐ Indian
- ☐ Middle Eastern
- ☐ African
- ☐ South American
- ☐ North American
- ☐ Choose not to answer
- ☐ Other (please specify)

* 14. What is your marital status?

- ◯ Married/de facto
- ◯ Separated/divorced
- ◯ Widowed
- ◯ Never married
- ◯ Choose not to answer

* 15. Does the person you provide care for have any other diagnoses that affect their behaviour?

- ◯ Yes
- ◯ No

You may provide details below if you choose.

16. Do you live with the person you provide care for?

- ◯ Yes
- ◯ No

Positive, Negative and Ambivalent Feelings: Potential Outcomes of Providing Care for People with Dementia

Some caregivers say that, despite all the difficulties involved in giving care to a family member with memory or health problems, good things have come out of their caregiving experience too. The following statements are a few of the good things reported by some caregivers. Please select the answer that best represents how much you agree or disagree with these statements.

* 17. Providing help to my loved one with dementia has made me feel more useful

Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
○	○	○	○	○

* 18. Providing help to my loved one with dementia has made me feel good about myself

Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
○	○	○	○	○

* 19. Providing help to my loved one with dementia has made me feel needed

Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
○	○	○	○	○

* 20. Providing help to my loved one with dementia has made me feel appreciated

Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
○	○	○	○	○

* 21. Providing help to my loved one with dementia has made me feel important

Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
○	○	○	○	○

* 22. Providing help to my loved one with dementia has made me feel strong and confident

Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
○	○	○	○	○

* 23. Providing help to my loved one with dementia has enabled me to appreciate life more

Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
○	○	○	○	○

* 24. Providing help to my loved one with dementia has enabled me to develop a more positive attitude toward life

Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
○	○	○	○	○

* 25. Providing help to my loved one with dementia has strengthened my relationship with others

Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
○	○	○	○	○

Positive, Negative and Ambivalent Feelings: Potential Outcomes of Providing Care for People with Dementia

The following questions address the extent to which your attitudes and feelings toward your care recipient (CR) are mixed or conflicted. Please answer each question with how often you experience these emotions.

* 26. I have mixed feelings toward my CR (tenderness-rage; love-hate, etc.)

Never	Sometimes	Frequently	Always
○	○	○	○

* 27. I feel divided or in conflict with respect to issues related to my CR

Never	Sometimes	Frequently	Always
○	○	○	○

* 28. I feel as much satisfaction as resentment (rage) by being a caregiver

Never	Sometimes	Frequently	Always
○	○	○	○

* 29. Although I have good relationships with other relatives, sometimes I get angry because they don't help more or because they don't offer more help

Never	Sometimes	Frequently	Always
○	○	○	○

* 30. I have at the same time positive and negative feelings towards my CR

Never	Sometimes	Frequently	Always
○	○	○	○

* 31. Although in general I believe that I care well, sometimes I feel that I'm a bad caregiver

Never	Sometimes	Frequently	Always
○	○	○	○

Positive, Negative and Ambivalent Feelings: Potential Outcomes of Providing Care for People with Dementia

Please read the following list of things which other people have found to happen to them because of their care recipient's (CR's) illness. Please select to what extent you have had any of the following experiences in the past six months.

* 32. Had financial problems

Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 33. Missed days at work (or school)

Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 34. Found it difficult to concentrate on your own activities

Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 35. Had to change your personal plans like taking a new job, or going on vacation

Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 36. Cut down on leisure time

Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 37. Found the household routine was upset

Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 38. Had less time to spend with friends

Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 39. Neglected other friends or family members' needs

Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 40. Experienced family frictions and arguments

Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 41. Experienced frictions with neighbours, friends, or relatives outside the home

Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 42. Became embarrassed because of your CR's behaviour

Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 43. Felt guilty because you were not doing enough to help

Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 44. Felt guilty because you felt responsible for causing your CR's problem

Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 45. Resented your CR because s/he made too many demands on you

Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 46. Felt trapped by your care giving role?

Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 47. Were upset about how much your CR has changed from his or her former self

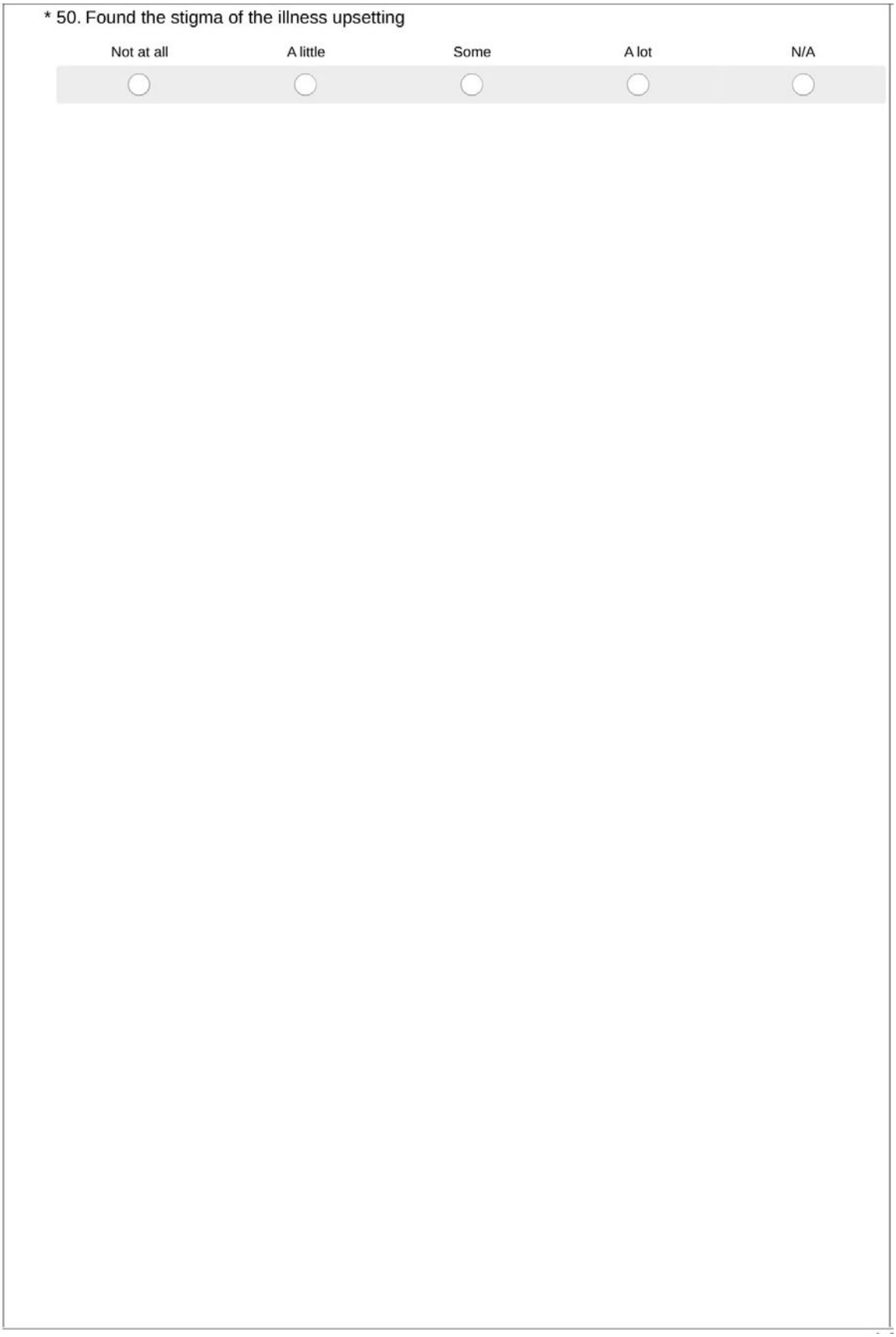
Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 48. Worried about how your behaviour with your CR might make the illness worse

Not at all	A little	Some	A lot	N/A
○	○	○	○	○

* 49. Worried about what the future holds for your CR

Not at all	A little	Some	A lot	N/A
○	○	○	○	○


* 50. Found the stigma of the illness upsetting
Not at all
A little
Some
A lot
N/A

Positive, Negative and Ambivalent Feelings: Potential Outcomes of Providing Care for People with Dementia

Please indicate your degree of agreement with the following statements*in general*. There are no right or wrong answers, and please try not to let your answers to one question influence your answers to other questions.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
* 51. In uncertain times, I usually expect the best.	○	○	○	○	○
* 52. It's easy for me to relax.	○	○	○	○	○
* 53. If something can go wrong for me, it will.	○	○	○	○	○
* 54. I'm always optimistic about my future.	○	○	○	○	○
* 55. I enjoy my friends a lot.	○	○	○	○	○
* 56. It's important for me to keep busy.	○	○	○	○	○
* 57. I hardly ever expect things to go my way.	○	○	○	○	○
* 58. I don't get upset too easily.	○	○	○	○	○

* 59. I rarely count on good things happening to me.

Strongly disagree	Disagree	Neutral	Agree	Strongly agree
○	○	○	○	○

* 60. Overall, I expect more good things to happen to me than bad.

Strongly disagree	Disagree	Neutral	Agree	Strongly agree
○	○	○	○	○

Positive, Negative and Ambivalent Feelings: Potential Outcomes of Providing Care for People with Dementia

The following questions ask about people in your life who provide you with help or support.
Each question has two parts.
For the first part, list all the people you know (it can be less than five), excluding yourself, whom you can count on for help or support in the manner described. You may either give the person's initials or their relationship to you. Do not list more than one person next to each of the numbers beneath the question.
For the second part, answer how satisfied you are with the overall support you have.
If you have no support for a question, please leave the first part of the question blank, but still rate your level of satisfaction. Do not list more than five people per question.

61. Whom can you really count on to distract you from your worries when you feel under stress?

1.
2.
3.
4.
5.

* 62. In relation to the above question, how satisfied are you?

Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied
○	○	○	○	○	○

63. Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

1.
2.
3.
4.
5.

* 64. In relation to the above question, how satisfied are you?

Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied
○	○	○	○	○	○

65. Who accepts you totally, including both your worst and your best points?

1.
2.
3.
4.
5.

* 66. In relation to the above question, how satisfied are you?

Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied
○	○	○	○	○	○

67. Whom can you really count on to care about you, regardless of what is happening to you?

1.
2.
3.
4.
5.

* 68. In relation to the above question, how satisfied are you?

Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied
○	○	○	○	○	○

69. Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps?

1.
2.
3.
4.
5.

* 70. In relation to the above question, how satisfied are you?

Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied
○	○	○	○	○	○

71. Whom can you count on to console you when you are very upset?

1.
2.
3.
4.
5.

* 72. In relation to the above question, how satisfied are you?

Very satisfied	Fairly satisfied	A little satisfied	A little dissatisfied	Fairly dissatisfied	Very dissatisfied
○	○	○	○	○	○

Positive, Negative and Ambivalent Feelings: Potential Outcomes of Providing Care for People with Dementia

The following questions address your current relationship quality with your care recipient (CR).

* 73. Taking everything into consideration, how close do you feel in the relationship between you and your CR?

Not at all close	Not very close	Slightly close	Very close
○	○	○	○

* 74. How is communication between you and your CR- how well can you exchange ideas or talk about things that generally concern you?

Not at all well	Not very well	Slightly well	Very well
○	○	○	○

* 75. In general, how similar are your views about life to those of your CR?

Not at all similar	Not very similar	Slightly similar	Very similar
○	○	○	○

* 76. Generally, how well do you and your CR get along together?

Not at all well	Not very well	Slightly well	Very well
○	○	○	○

Positive, Negative and Ambivalent Feelings: Potential Outcomes of Providing Care for People with Dementia

The following set of questions asks you to indicate what you generally do and feel, when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress.

Then respond to each of the following items by selecting one of the response choices. Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Indicate what YOU usually do when YOU experience a stressful event.

* 77. I turn to work or other activities to take my mind off things.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 78. I concentrate my efforts on doing something about the situation I'm in.

I usually don't this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 79. I say to myself "this isn't real".

I usually don't this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 80. I use alcohol or other drugs to make myself feel better.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 81. I get emotional support from others.

I usually don't this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 82. I give up trying to deal with it.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 83. I take action to try to make the situation better.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 84. I refuse to believe that it has happened.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 85. I say things to let my unpleasant feelings escape.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 86. I get help and advice from other people.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 87. I use alcohol or other drugs to help me get through it.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 88. I try to see it in a different light, to make it seem more positive.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 89. I criticise myself.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 90. I try to come up with a strategy about what to do.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 91. I get comfort and understanding from someone.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 92. I give up the attempt to cope.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 93. I look for something good in what is happening.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 94. I make jokes about it.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 95. I do something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 96. I accept the reality of the fact that it has happened.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 97. I express my negative feelings.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 98. I try to find comfort in my religion or spiritual beliefs.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 99. I try to get advice or help from other people about what to do.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 100. I learn to live with it.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 101. I think hard about what steps to take.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 102. I blame myself for things that happened.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 103. I pray or meditate.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

* 104. I make fun of the situation.

I usually don't do this at all	I usually do this a little bit	I usually do this a medium amount	I usually do this a lot
○	○	○	○

Positive, Negative and Ambivalent Feelings: Potential Outcomes of Providing Care for People with Dementia

Please read each statement and choose how much the statement applied to you<u>over the past week.</u> There are no right or wrong answers. Do not spend too much time on any statement.

* 105. I found it hard to wind down.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often	Applied to me very much, or almost always.
○	○	○	○

* 106. I was aware of dryness in my mouth.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often	Applied to me very much, or almost always
○	○	○	○

* 107. I couldn't seem to experience any positive feeling at all.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always.
○	○	○	○

* 108. I experienced breathing difficulty (e.g., excessively rapid breathing, breathlessness in the absence of physical exertion).

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always.
○	○	○	○

* 109. I found it difficult to work up the initiative to do things.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always
○	○	○	○

* 110. I tended to over-react to situations.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always.
○	○	○	○

* 111. I experienced trembling (e.g., in the hands).

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always.
○	○	○	○

* 112. I felt that I was using a lot of nervous energy.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always.
○	○	○	○

* 113. I was worried about the situations in which I might panic and make a fool of myself.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always
○	○	○	○

* 114. I felt that I had nothing to look forward to.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always.
○	○	○	○

* 115. I found myself getting agitated.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always.
○	○	○	○

* 116. I found it difficult to relax.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always.
○	○	○	○

* 117. I felt down-hearted and blue.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always.
○	○	○	○

* 118. I was intolerant of anything that kept me from getting on with what I was doing.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always.
○	○	○	○

* 119. I felt I was close to panic.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always.
○	○	○	○

* 120. I was unable to become enthusiastic about anything.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always.
○	○	○	○

* 121. I felt I wasn't worth much as a person.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always
○	○	○	○

* 122. I felt that I was rather touchy.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always.
○	○	○	○

* 123. I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase, heart missing a beat).

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always.
○	○	○	○

* 124. I felt scared without any good reason.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always.
○	○	○	○

* 125. I felt that life was meaningless.

Did not apply to me at all.	Applied to me to some degree, or sometimes.	Applied to me a considerable degree, or often.	Applied to me very much, or almost always.
○	○	○	○

Positive, Negative and Ambivalent Feelings: Potential Outcomes of Providing Care for People with Dementia

Thankyou for taking the time to complete the survey!

If you have experienced any distress in answering any of the questions in the survey please note the following services that could be of use:
Lifeline (24 hour service): 13 11 14
Mind Carer Helpline: 1300 554 660
Carers Australia: 1800 242 636

Please email [redacted] if you wish for a summary of the findings to be sent to you when completed.

126. Thinking about the outcomes of caregiving, would you like to add anything about your experience? We would love to hear your thoughts, whether you think it will contribute to the study or not.